MASTER OF PHILOSOPHY

Dentists and their Willingness to Treat Adolescents with Learning Disabilities a Survey of Accessibility in Primary Dental Care

Coyle, Catherine

Award date:
2011

Dentists and Their Willingness to Treat Adolescents with Learning Disabilities: A Survey of Accessibility in Primary Dental Care

A Thesis Submitted for the Degree of

MASTER OF PHILOSOPHY

in

The School of Medicine

University of Dundee

Catherine Coyle BDS (Hons), MFDS, MPaedDent

November 2010

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List of abbreviations

LD	Learning Disabilities
NI	Northern Ireland
EHSSB	Eastern Health and Social Services Board
NHSH	NHS Health Board; Highland
GDS	General Dental Services
SDS	Salaried Dental Services
GDP	General Dental Practitioner
W2TS	Willingness to Treat Score
MCN	Managed Clinical Network

Acknowledgements

I would like to express my sincere gratitude to my supervisor, Professor Ruth Freeman, University of Dundee, for all her expertise, time, patience and support to see this work to completion.

I am also very grateful to Professor Gerry Humphris for his advice and encouragement throughout and particularly his expertise in path analysis: his knowledge and skills were invaluable.

I would like to thank the dentists in both the Salaried Dental Services and General Dental Services in Scotland and Northern Ireland who kindly participated in the survey.

I am indebted to many of the staff in the Dental Health Services Research Unit for their kindness and assistance during my work in the Unit.

Many thanks to my husband, Robin, for supporting me throughout all my studies thus far.

Declaration

I hereby confirm that I am the author of this thesis. All the references cited have been consulted by myself, that the work of which the thesis is a record has been done by myself and it has not previously been accepted for a higher degree.

Catherine Coyle

Abstract

The aim of this study is to examine primary dental care practitioners' willingness to treat adolescents with learning disability (LD) in two contrasting areas of Northern Ireland (NI) and Scotland using Cohen's accessibility 'dental health professional' factors (Cohen, 1987).

A non-probability sample of all primary care dentists in the more urban EHSSB [NI] and remote and rural health board of NHS Highland (Scotland) (537) in both the Salaried Dental Services (SDS) and General Dental Services (GDS), were invited to take part in the survey. The main outcome measures were demographic profile, previous undergraduate and postgraduate experience, knowledge of LD and its' management in the clinical setting, numbers of adolescents with LD treated, attitudes towards individuals LD and willingness to treat this patient group.

The data was analysed by t-tests, Analysis of Variance (ANOVA), factor analysis and pathway analysis. Three hundred SDS and GDS dentists completed the self-administered questionnaire. The valid response rate was 61%. There was no significant difference in numbers of adolescents with LD treated in the health boards examined in NI and Scotland. Willingness to treat adolescents with LD was positively associated with a social model perspective on disability. This in turn translated to the development of positive attitudes. Conversely, dentists who held a

medical model of disability, were found to have more negative attitudes and were less willing to treat adolescents with LD.

The acquisition of knowledge and increased level of undergraduate training in relation to LD and its' management would appear to strengthen a social model perspective and hence promote positive attitudes and willingness to treat those adolescents with LD. Meanwhile, undergraduate training and knowledge pertaining to disability did not significantly contribute to dentists whose beliefs underpinned the medical model of disability. These findings were consistent for dentists working in two distinct health board areas of the United Kingdom and within both the SDS and GDS. Therefore area of work *per se* (ie rural or urban location) is not an influential factor in willingness to treat and hence unmet treatment need. This does not exclude the possibility that area of work may have a bearing on willingness to treat as a consequence of university attended for their undergraduate training.

It is recommended that suggestions for undergraduate training and postgraduate education are commensurate with Government policy (DoH, 2007) on the mainstreaming of dental services for special care patients.

1.0 Introduction

Traditionally, the passage from childhood to adulthood – the transition years – is marked in a variety of ways, many of which recognise the complications, responsibilities and indeed opportunities which have come to define this period in traditional Western society.

Yet increasing numbers face much more turbulent waters in making this transition. Those children with learning disabilities (LD) must take their health problems with them as they grow into adults. This task is frequently made more complicated by inadequate planning of the handover from one service to another, or worse still, no arrangements made at all.

The past three decades have seen major changes in the pattern of care and support for people with LD as they enter adulthood. The concept of normalisation has led to closures of long-stay institutions with a change in emphasis to community care. The changing role of special school and adult services has led to greater integration into mainstream education and employment. This has created new challenges in targeting services for this vulnerable group. There are valid concerns that deinstitutionalisation and subsequent integration into the community, has resulted in reduced frequency of contact with dental services and deteriorating oral health (Griffiths, 2000).

The media has reflected these concerns. In November 2004, a headline in 'The Guardian' newspaper captured the essence of the problem; *"Learning disabled face lifelong exclusion, charity warns"*. Several passages in the article, by David Batty, were particularly noteworthy:

> *"…people with learning disabilities remain ostracised from their local communities, despite a range of Government reform."*
>
> *"The report Hidden Lives [by the social care charity Turning Point], criticised professionals' low expectations of people with learning disabilities…"*
>
> *"People with a learning disability have not benefitted from the Government's efforts to end social exclusion and this is despite the fact that they are amongst the most marginalised groups in society".*

It is disheartening then, several years later, to encounter another headline painting an equally bleak picture as that of three years previously; *"NHS ignoring the human rights of people with learning disabilities"* (Carvel, The Guardian, December 2007). Despite Government policy, there is little evidence of perceptible improvement.

Dental care for those with learning disabilities is particularly controversial. Media attention has focussed on excessive waiting times for treatment, especially under general anaesthesia (GA). In Northern Ireland in the former Eastern Health and Social Services Board (EHSSB), the waiting time for assessment for special needs

patients in 2005 was estimated to be in the region of two to three years. Despite the fact that there are approximately 400 dental practitioners within the EHSSB, the dental needs of those with learning disabilities appear to be unmet.

In addition to the issues of access and equality, the difficulties specific to adolescents with learning disabilities must be raised. There would appear to be little recognition of the needs of young people with learning disabilities in making the transition from child to adult services. Care during adolescence clearly inter-relates that for children and adults, yet there is a risk that those discharged from paediatric services may lose contact with dental services altogether, particularly if this coincides with leaving or changing schools. Those transferred to the adult department often face long waiting lists with little provision for emergency care in the interim. It therefore seems appropriate that further research in relation to accessibility of care targets this population specifically.

It has been suggested that the shift towards private practice in the UK has increased onward referral of 'difficult cases' elsewhere, hence leading to congestion at the tertiary care level. Yet many people with learning disabilities may accept treatment in the community – Davies et al (1988) have also suggested that although around 2% of the UK population has a learning disability, only a small number are severe enough to warrant hospital care due to behavioural or concurrent medical problems. These conflicting research findings seem to reaffirm the complexity of

dentists' decisions to see patients with learning disabilities, based on financial, geographical, attitudinal and educational factors.

It may therefore be useful to examine dentist's behaviour, with respect to management of adolescents with learning disabilities, working under different financial constraints (general dental services and salaried dental services) and geographical constraints (rural vs urban), in order to determine the influence of manpower and geography on service provision for this group (Cohen, 1987).

It would seem that Cohen's (1987) accessibility factors with regard to the 'dental health professional level' may be of particular relevance for the dental care of adolescents with learning disability. Specifically, from the perspective of the dental health professional, how do previous educational experiences and attitudes influence their willingness to treat this group of patients? Therefore, there is a need to operationalise Cohen's 'dental health professional level' factor in order to examine primary dental care practitioners' willingness to treat adolescents with LD in order to increase access to care.

This survey first, investigates the historical context of care for those with LD and its' relevance to present day care, through a narrative literature review. The aims and objectives are then stated in Chapter 3. This is followed by Chapter 4 which provides a description of the methodology of the survey. The questionnaire used

for the survey is included in the appendix. Chapter 5 reports the results of the survey and the reader is directed to the appendix where appropriate for additional information. Chapter 6 then discusses the results the context of the literature and previous research. In the light of this discussion, a series of recommendations are made. Finally, a conclusion draws together the findings of the study the perspective of the client group itself and points to future research in the subject of dental care for those with LD.

2.0 Literature Review

Part 1: Historical Perspectives of Learning Disabilities

2.1 Exploring the history

2.2 What is learning disability?

Part 2: Present Day Barriers to Accessing Care for People with Learning Disabilities

2.3 Understanding the Issues

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2.5 Conclusion

Part 1: Historical Perspectives of Learning Disability

"We need the past in order to be able to understand ourselves. We need it in order to believe in our future. If we have come from nowhere, where are we going to?"

[Hall Carpenter Archives, 1989, (cited in Atkinson 1997)]

2.1 Exploring the History

2.1.1 From Ancient Greece to Early Modern Britain

Learning disability has been a source of speculation, fear and scientific enquiry since the beginning of humankind. It has been regarded in turn as a religious, administrative, eugenic, educational and social problem, in an attempt to understand and manage its existence (Clarke, 1986). Hence a range of attitudes and beliefs have been held in respect of affected individuals; sub-human organism, menace, object of dread, object of pity, holy innocent, diseased organism, eternal child (Wolfensberger, 1972).

The existence of individuals with disabilities can be traced back to the time of primitive people who killed the weak and deformed, considered to be a burden on the tribe (Roper 1913, cited in Atherton 2007). Their existence is also recorded in Ancient Greek writings – Plato referred to those "*whose psychological constitution is incurably corrupt*" (cited in Neugebauer 1996) and were therefore not welcomed in the development of civilised society.

It was not until a much later period, with the advent of Christianity, that attitudes towards the 'idiot' saw a significant change, brought about through Christian theology. From Christianity came doctrines of compassion and charity, urging the need to "*comfort the feeble minded…be patient with all men*" (1 Thessalonians 5:14). The Christian doctrine of 'original sin', carried with it a certain status of

equality for the 'idiot'. This philosophy was embellished by St Augustine (AD 354 – 430), who, in discussing original sin, connected his argument to children. He observed that because children could not 'reason', they could not be held responsible for their 'sins'. Hence they were to be considered 'holy innocents' (Concannon, 2005).

Since, 'holy innocents' lacked the capacity to knowingly sin, thus began the association between children and those deemed 'idiots', an association and imagery which continued throughout history (and to some extent, the present day).

By the Middle Ages, demonological beliefs about the aetiology of learning disability ran concurrently with Christian theology. According to Szymanski and Crocker,

> "*Mental illness and mental retardation (which were lumped together) were attributed to supernatural causes and were considered in the province of priests and philosophers. Although a few retarded persons did have a career as 'court fools' others were exploited, persecuted and exorcised".*
>
> (Cited in Neugebauer, 1996)

These beliefs resulted in the simultaneous persecution and worship of people with learning disabilities. In some communities, the mentally deficient brought luck by drawing God's wrath on themselves, thereby serving the role of scapegoats, whilst

in others, according to records depicting changelings, persecution of deviants included placement of them on red hot shovels, burning on ashes, or the drinking of poison (Eberly, 1988).

Yet, despite the treatment of people with learning disabilities during this period, they were still integrated within communities and not drawn to the attention of the state. It is also noteworthy that there was no distinction between functional and organic disorders.

In early modern Britain however, these differences became accentuated. It was the State, drawing on the notion of the 'innocents', not the Church that attempted to determine the status of the 'idiot', regarding such rights as land ownership.

De Prerogativia Regis (1325) (cited in Neugebauer, 1996) was the first piece of legislation that sought to exert a degree of state paternalism over those with learning disabilities. No longer a source of amusement, English Law, became concerned with the need to control the 'idiot'. Thus emerged a legal dichotomy between idiocy and lunacy. 'Idiots' (or 'natural fools') were seen as having a permanent disability from birth, involving failure of development of mental capacity beyond that of a child. Legally then, this definition excluded types of learning disability arising from post natal sickness and 'accidents'. This group was distinct from 'lunatics', or 'persons non compos mentis' (now recognisable today as the

mentally ill) who may have periods of temporary remission or lucidity, or even complete recovery.

An early 17th Century legal dictionary clarified this distinction, alluding to way of establishing the diagnosis:

> "*Idiot is he that is a fool natural from his birth and knows not how to account or number twenty pence, nor can not name his father or mother, nor of what age himself is, or such like easy and common matters; so that it appears he has no manner of understanding or reason, nor Government of himself, what is for his profit or dis-profit."*
>
> (Neugebauer, 1996)

The practical consequence of De Prerogativia Regis was that for people with learning disabilities ('idiots'), the permanence of their condition meant that the king was entitled to take possession of their land and collect the revenues from their estate, until death, when it could be transferred to their rightful heirs. In contrast, state control of the land of those with mental illness ('non compos mentis', 'lunatics') could only be maintained until their recovery. This was not the only consequence of the law. For 'idiots', the Crown reserved the right to retain any revenue not required to provide for their 'bare necessities'.

However, for ‘lunatics’, the Crown was obliged to return any revenue that had not been used to maintain them and their family to a standard that equated to their social rank (Neugebauer, 1996). It was not until the sixteenth century, that the law was amended to ensure that the rights of those with learning disabilities and mental illness were equal.

The Tudor Period exemplified early community care – whilst the overall care of ‘idiots’ and ‘lunatics’ was the responsibility of the Crown, direct care was undertaken by private individuals who bought this privilege by entering into bonds with the Crown, obliging them to execute the trust responsibly. Although this allowed people to remain in their communities, inevitably there was financial exploitation of the role. The court, unable to mandate good will, subsequently sought guardians who were bound to the ‘idiot’ by affection;

> *“The nearest of kin…sound in religion, of good governance in their own families…no greedy persons, no stepmothers.”*
>
> (Neugebauer, 1996)

‘Idiocy’ was therefore to be viewed as mainly a domestic family problem. Only when care broke down, often if the burden of care resulted in family poverty, did the situation become a matter of public concern. At this stage, the segregation of people considered to be a social and economic burden, became a real option. With the introduction of the Elizabethan Poor Law Act in 1601, came swift movement

towards incarceration and confinement in work houses (Concannon, 2005). The growth of these early institutions was rapid and as wide-spread institutional care resulted in a distancing of 'idiot' and 'lunatics' from the community, social negativity grew stronger.

2.1.2 The Upsurge of Eugenics

Within the industrialising and urbanising society of the late nineteenth century, the 'feeble minded', as they had come to be known, became a financial burden. There existed the additional perceived threat that this group posed by the way they seemed to propagate their own kind. This, it was believed, would lead to the degeneration of society as a whole, resulting in national crisis:

> "*The danger lies in the fact that these degenerates mate with healthy members of the community and constantly drag fresh blood into the vortex of disease and lower the general vigour of the nation."*
>
> [Tregold, 1909 (cited in Atherton, 2007)]

A number of hypotheses were proposed as to the exact cause of degeneracy within society. In 1857, Morel (cited in Gelb, 1995) hypothesised that degeneracy was a result of poverty or sinful living, identifiable by a number of behavioural and physical 'stigmata'. (Table (i))

Table (i): Behavioural and physical stigmata of 'degenerates'.

Physical	Behavioural
• *Asymmetry of head or face* • *Open protruding mouth* • *Long arms* • *Shortened fingers* • *Jug handled, large, or small ears* • *Cleft palate*	• *Masturbation* • *Absence of shame* • *Fearfulness* • *Tendency to have strong emotional response to music* • *Insensitivity to pain*

It became a widely held belief that the 'feeble minded' were the primary cause of many of the vices present in society. Control of the propagation of the 'feeble minded' therefore was imperative. Thus was the evolution of the Eugenics Movement, associated with Darwinian biology, which involved many progressive thinkers in the field of Social Policy. The term eugenics, taken from the Greek meaning 'good born', was first coined by Sir Francis Galton (1822 – 1911) in 1883. He defined his theories as *"the science of improvement of the human race germ plasma through better breeding"* (Concannon, 2005).

Galton believed that 'feeble mindedness' was a single unit of inheritance that could be transmitted through generations of the same family. Environmental factors such as education, had no bearing on this transmission. Eugenicists believed that the key

to creating better society was "*proper breeding of good stock*" (Concannon, 2005), natural selection alone being unreliable for desirable survival of the human race. Two characteristics of the eugenics movement emerged – first the promotion of procreation of 'fit' individuals (positive eugenics) and secondly, the need to restrict breeding of the 'unfit' (negative eugenics) (Radford, 1991).

Progression of negative eugenics in Britain in 1913 ultimately failed to convince legislators of the need for forced sterilisation, although subsequently the Wood Report of 1929 did recognise the need for detainment and recommended the immediate incarceration of 100,000 individuals. In Nazi Germany however, the idea of control of social deviants was put into practice – the programme of sterilisation of those with learning disabilities extending to one ultimately of elimination. This culminated in rejection of eugenics in polite society, post Second World War. The British direction taken on the matter post 1945, formed the basis of current policies about choices and rights for those with learning disabilities.

2.1.3 The Rise and Decline of Institutions

The Mental Deficiency Act of 1913 identified four categories of mental defect; 'idiots', 'imbeciles', 'feeble-minded' and 'moral defectives'. The definition, however, spanned such a wide and loose range of meanings, that often patients were committed to an asylum (as institutions became known), for little more than a one off anti-social act (Concannon, 1995). A distinction was sought to segregate

the mentally ill from those with learning disabilities, with the aim of 'training' the latter group towards playing a more positive role. The teaching regime held out the hope that individuals with learning disabilities could develop skills of self-care. With 'high grades' the eventual goal was to teach the skills of reading and writing. However, with the degeneration of society in the early half of the twentieth century, asylums became more custodial than reforming in their nature.

With the implementation of the NHS Act in 1946, the control of asylums was transferred from local councils to Regional Hospital Boards (Atherton, 2007). To ensure complete containment, 'inmates' lived, worked and undertook leisure activities on the same site, thus minimising contact with the community. Males and females were segregated to reduce the risk of sexual relationships. Mable Cooper recounts her experience in St Lawrence's Hospital, Bedford, in 1952;

> "*There was bars on the windows…it was just like a prison. Of course it was called a nuthouse in them days. You didn't have toys…they would just get broken and thrown through the bars in the window and get caught in them…"*
>
> *"On the male side, you see they're different. You couldn't mix with the men…"* (Cooper, 1997)

The institutional system also exercised complete control and tyranny over 'inmates' through reward and punishment. Fido and Potts recall;

"*You know if we did something wrong we had to be in us nighties all day and be punished. Couldn't have your visitors to see you."*

(Fido and Potts, 1997)

By the 1950's institutions were beginning to be perceived not as solutions as thought previously, but as problems involving stigmatisation and depersonalisation. In this context, the process of institutionalisation was recognised as accentuating the differences between 'inmates' and the outside world, thus providing a self-sustaining rationale for institutional confinement (Goffman 1961, cited in Wright and Digby 1996).

Sociological studies undertaken at that time (Tizard and O'Connor, 1952) demonstrated that many institutionalised individuals did in fact have the intellectual and social capabilities to live in the community. High profile scandals unfolded, the most infamous being that Ely Hospital which drew attention to impoverished and squalid conditions (Howe Report 1969, cited in Concannon 2005). Public abhorrence to these events was reflected in modified political agendas. There had already been an end to compulsory certification, provided by the New Mental Health Act in 1959 (HSMO, 1959); this was subsequently augmented by the White Paper; *Better Services for the Mentally Handicapped* (DHSS, 1971). This advocated a 50% reduction in hospital places by 1991, provision of day-care and retraining of hospital staff. The paper (DHSS, 1971) represented a turning point in

the literature in that it recognised the importance of support from the family, friends and the voluntary services, in the care of people with learning disabilities.

Hence a philosophy of normalisation evolved. In an influential book, "*The Principles of Normalisation in Human Services"* (1972), the psychologist Wolfensberger drew on Goffman's ideas of deviance and labelling. Wolfensberger (1972) identified that state facilities had served to draw attention to the negative or devalued qualities of individuals with learning disabilities and that a new initiative was needed to provide an appropriate framework for restoration of human dignity. Normalisation was thus defined as:

> "*The utilisation of means which are as culturally normative as possible, in order to establish and/maintain personal behaviours and characteristics which are as culturally and as normative as possible."*
>
> [Wolfensberger, 1972 (cited in Gates, 2007)]

The concept of normalisation and the developing culture of human rights, as emphasised by the (1971) UN declaration on the *Rights of Mentally Retarded Persons* (UN General Assembly Resolution, 1971) and the Jay Committee into Mental Handicap and Care (HSMO, 1979), culminated in the NHS and Community Care Act (HMSO, 1990). This Act sought to provide the structures necessary to enable people to remain in their own homes, where possible, thereby reducing the demand for long term care. Central to these themes was the provision of the

service tailored to the needs of individuals and the introduction of community care assessments, undertaken by social services with the assistance of health care professionals. The NHS and Community Care Act (1990), set the scene for further improvement of services for individuals with learning disabilities through a more generalised policy and legislation. This included the Disability Discrimination Act (HMSO,1995) with its subsequent revisions, the Human Rights Act (HSMO, 1998) and other guidance documents such as the Disability Rights Commission (DRC, 2006), aimed at improving the quality of healthcare for this group

The most recent major piece of policy on learning disabilities was the Government White Paper *Valuing People* (DoH 2001). It aimed to improve the quality of life of people with learning disabilities and their families, through promotion of rights, inclusion, choice and independence, in areas including health, education, housing, employment and leisure. In particular, the paper addressed the issue of support for those experiencing a period of life transition, such as the adolescent moving from child to adult services. Current Government reviews of the progress being made by *Valuing People* (DoH, 2005) report both success and failure, with inconsistent progress across the country. Furthermore, it has been identified that significant barriers exist that have maintained a disparity between policy, ideology and the practice of services (McNally, 2004).

Nevertheless, have the lessons of history been learnt – that is, can the limitations of current service philosophies be held solely accountable for the fact that people with learning disabilities are still experiencing barriers to their social inclusion (Batty, 2004) and health care (Keywood and Flynn, 2006; Kroll et al, 2006)?

2.1.4 Past Meeting Present

So what is the relevance of the past? There can be no doubt that a study of the history of learning disabilities is a means of giving a sense of direction. It would appear that the attitudes and patterns of healthcare that exist today are rooted firmly in the past. Recent Government policy sees a re-emergence of concepts initially identified by the historical controls on the lives of people with learning disabilities throughout the ages, such as the church and state. These include the role of the family and the need for protection. Indeed, community care initiatives have traditionally been viewed as a distinctive feature of the 1970's, but should more accurately viewed as the common historical response to learning disabilities. And today, as more and more people with learning disabilities reside in the community, in many cases closer to their relatives, the forms of care that transfer the monies from local authorities and the decision making for welfare back to the individuals and their carers present opportunities for personalised care (DoH, 2007). This process can provide people with disabilities the option to choose and potentially engage with their communities. The philosophy of Philippe Pinel (1745 – 1846), a prominent French physician who pioneered the humane treatment of the

'idiot', through replacement of cruelty with kindness, obviously has resonances with today's policies.

Commitment to education – the optimistic expectation of the early era of the 'asylum' – would now be considered as progressive. Consider also the issue of eugenics – alongside current statements of human rights, we see new scientific developments emerge which may herald a revival of eugenics under a new guise. It is unquestionable that eugenics, long ingrained in the human psyche, has had a long lasting influence on society about those who are 'different'.

It is irrefutable that historical perspectives of learning disability present a picture of a move from misery and ill treatment to enlightenment and eventually acceptable care (Bredberg, 1999). Historical attitudes and beliefs have formed the cornerstone of today's social policy and legislation for the delivery of care. However, continuing attempts to meet the changing needs of patients with learning disabilities will inevitably need further evolution and progression of current philosophies. In this process, let us not forget the rationale of understanding the history;

"*Those who can not remember the past are condemned to repeat it."*

(Santayana, cited in Taylor, 1996)

2.2 What is Learning Disability?

The term *Learning Disability* used in this review refers to significant intellectual impairment and deficits in social functioning or adaptive behaviour (basic everyday skills) that have been present from childhood (DoH, 2001).

2.2.1 From Early Classification – Have We Progressed?

Langdon Down (1828 – 1896) is probably the most famous name associated with early classification of learning disability. His system classified differing grades of 'idiot', based on ethnicity.

Information was gathered by completion of post-mortems of former patients, with the analysis of the cranial capacity and anatomical differences. Langdon Down believed that these groups of individuals represented earlier forms of the human race (such as the Mongolian tribes). His findings were published in 1887 and including the "Mongoloid" term that later came to bear his name "Down's Syndrome" (Borthwick, 1996).

There can be no doubt that defining and classifying disability has been, and still remains, a difficult task. The literature (Neugebauer, 1996; Concannon, 1995) highlights how different historical perspectives have been reflected in the language adopted, thus helping us to understand past values and attitudes. It is interesting that in a culture of political correctness and human rights, yesterday's definition has

become today's term of abuse; 'idiot', 'moron', 'mongol', 'moral defective', have been replaced by more socially acceptable terms in recent years. So why then, in this era of political correctness, equality and human rights, is the provision of equitable health care (including dental care) for this group debatable?

There can be no doubt that progress has been made; on reading the historical literature on learning disability, it is readily apparent that yesterdays' definition has become today's term of abuse. 'Idiot', 'moron', 'mongol', 'defective', has thankfully been replaced by more socially acceptable terms in recent years. Yet, delve deeper – these seemingly fundamental principles of progress and attitudes can even be questioned: the prominent medical text, 'Review of Medical Physiology' by Ganong, published in 2005, refers to the seldom used term "Mongolism". Is it a case that the supposedly enlightened health care professionals have regressed or even failed to progress with the basics?

Today's terminology has still to deal with the basic dilemma identified by Yespen in 1941 (Cited in Race, 1995). He concluded that,

> "*After analysing one hundred or more criteria and descriptions, making up the definitions which have appeared in the literature…none actually defines mental deficiency. All are descriptive of the results of mental deficiency."*

From this tendency of the medical profession to assess symptoms and patient need, prescribe an intervention and facilitate a cure, has emerged what has come to be described as the 'medical model' of disability. The principle of return to bodily and sensory 'wholeness' is grounded in the medical model. The result is a focus on what the disabled individual cannot do, carrying assumptions of their anticipated passivity. Today's terminology and definitions are therefore still located firmly in the medical model. Yet Oliver (1990) has suggested that disability stems from the failure of the social and physical environment to take account of the needs of disabled people. Thus, according to this 'social model', it is society that labels a person as having a 'learning disability'.

2.2.2 Labelling and Stereotypes

Labelling has long been associated with disability; historical accounts are inundated with descriptions from religious texts, superstitions, school playgrounds and the workplace. Over time, it would seem that labels have emerged from the implicit associations with 'unworthiness' that lie at the heart of society's judgement of disability as a deviance (Johnstone, 2001).

Stigma, as an extreme form of labelling, has come to be associated with some of the more negative features of definition. The most recent influential analysis of stigmatisation is that of Goffman, who defined stigma as an attribute which is deeply discrediting.

> "*An individual…possesses a trait…that turns those of us whom he meets away from him. He possesses a stigma, an undesired differentness from what we had anticipated."* [Goffman, 1963 (cited in Scambler, 1997)]

Thus, rather than attaching a label to someone as disabled we should be asking; "What is the person disabled for? Not, what is their disability?" (Nunn, 2000). Bury (1996) has suggested that disability is the product of our terminology and practices, that hence exclude individuals who deviate from socially constructed norms.

> "*It is not the inherent nature of disability that matters, but the labelling process which categorises people by virtue of their position in relation to the dominant structures and values of the society."* (Bury 1996)

While health care professionals today take measures to avoid labelling people with learning disabilities, some form of terminology must be available to categorise groups to facilitate communication, funding and administrative decision-making. There has been little agreement on definitions between scientific, social and medical professions. However, a set of acceptable terms of reference has been developed which will subsequently be described.

2.2.3 Defining Disability

In 1980, the World Health Organisation (WHO) offered a definition it hoped would be acceptable to practitioners, regardless of their field. In *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) published in 1980, it presented the following classification (Table (ii)):

Table (ii): Classification of impairments, disabilities and handicaps.

Impairment
Any loss or abnormality of physiological or anatomical structure or function.
Disability
Any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being.
Handicap
A disadvantage for a given individual, resulting from an impairment or disability, which limits or prevents fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual.

The ICIDH has come under severe criticism by organisations managed by disabled people (French, 1994). Although the system progresses from a narrow medical definition and acknowledges that disability has social dimensions, both disability

and handicap are viewed as arising from impairment rather than from social and environmental causes, which are taken for granted and assumed to be fixed.

Secondly, the use of the term 'handicap', is considered to be offensive by many people with disabilities, largely due to its historical allusions to 'cap in hand', charity and begging (Barnes 1992, Albrecht 1992). Lastly, the system fails to address issues such as education, employment and housing, with the concept of 'normality' being accepted without recognition of cultural determinants.

'Mental handicap' is clearly therefore an unacceptable term in today's society. Hence in the UK today, the usual means of describing individuals with significant developmental delay that results in incomplete achievement of the 'normal' milestones in human development is learning disability. It should be pointed out that the term 'learning disability' is relatively new – it has been suggested that it was first introduced in 1991 by Stephen Dorrell, then the Minister for Health in a speech to Mencap (Gates, 2007). It has since been defined by the Department of Health (DoH, 2001) and Clinical Guidelines (British Society of Disability and Oral Health; The Royal College of Surgeons of England Faculty of Dental Surgery, 2001):

> "*A significant impairment of intelligence and social functioning acquired before adulthood".* (BSDOH; RCSEng, 2001)

Historically, intelligence testing was introduced as a means of defining the degree of intellectual deficiency that was needed to constitute a 'defective' child. In 1905, Alfred Binet and Victor Simon published the first set of tests linking mental and chronological age. Later, the German psychologist Stern, developed this work into the concept of the intelligence quotient or IQ (Wright and Digby, 1996). Consequently, the degree of disability has in the past been characterised by how far an individual is from the normal distribution of IQ for the general population, with less than 70 being diagnostic of learning disability. Intelligence tests were widely used during the 1960's and 1970's, however in recent years they have received much criticism. Emerson et al (2001) believe that such categories represent static measures that tell us nothing of the needs of the individual (which may vary between individuals even if their IQ's are equal). Furthermore, definition by IQ serves to segregate individuals into predetermined services.

Nevertheless, decision making in the provision of appropriate services for an individual with learning disabilities can be guided by some form of categorisation. Therefore the following broad categories are often adopted as an aid to management.

Mild Learning Disability

People with low support needs; able to lead relatively independent lives.

Moderate Learning Disability

People with medium support needs who require assistance with a wide range of everyday skills, though they are able to undertake a number of tasks for themselves independently.

Severe/Profound Learning Disability

People with high support needs. Typically require 24-hour care as they are able to carry out only a few, if any, activities of daily living. They may have additional physical and/or sensory difficulties and significant medical problems.

(BSDOH; RCSEng, 2001)

The importance of examining the ways in which disability is defined cannot be underestimated, for attitudes and behaviour towards people with learning disabilities and healthcare services are based to some extent on these definitions. As described by Oliver (1996):

> "*The 'lack of fit' between able bodied and disabled peoples' definitions is more than just a semantic quibble. It has important implications both for the provider of services and the ability to control ones life."*

The discussion of disability needs to be part of a wider debate about social inclusion and healthcare. An understanding of disability therefore requires an analysis of the

input of social factors in different environmental, historical and cultural settings. Barnes, as a theorist of the social model of disability, defines disability as

> *"The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers"*
>
> (Barnes, 1994)

Social model theorists have therefore focussed on policy and planning, rather than examining interactions between people, on the basis that social structures can serve to disable people, whatever the intentions of the individuals.

It could be said that ideologies, theories and practices in respect of the terminology of disability, have both enhanced and tarnished the lives of people with learning disabilities. For example, fear and the desire to protect individuals with disabilities led to segregation, thus depriving many people of the progressive treatments to which they were entitled. The terms 'normalisation' and 'learning disability' used in the UK have assisted development of self-respect and opportunities for many people, but inconsistent terminology still leads to misunderstanding among health care professionals, particularly those who are not directly involved in this area. Similarly, the interpretation of 'equality' could be taken in the over-simplistic, inappropriate knowledge and belief that good care is about 'treating everyone the same'. Rather, it is about treating people with learning disabilities as unique individuals whose lives and experiences have been shaped by social inequalities.

Part 2: Present Day Barriers to Accessing Healthcare for People with Learning Disability

"Disabled people, whatever the origin, nature or seriousness…have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life as normal and full as possible."

The Declaration on the Rights of Disabled Persons, UN (1975)

"Everyone has the right to a standard of living adequate for the health and wellbeing of himself and his family including…medical care and social services."

Universal Declaration of Human Rights, UN (1948, Article 25)

2.3 Understanding the Issues

2.3.1 Prevalence of Learning Disabilities

Calculating the prevalence of learning disabilities is problematic as manifestations may not become apparent for some time in childhood. Furthermore, if IQ alone is used as an indicator of learning disability, then many people with an IQ below 70 may never come into contact with the community services.

Historically however, there has been a general consensus that the overall prevalence of moderate and severe disabilities is approximately 3 – 4 per 1000 of the population (DoH 1992). The Department of Health has also suggested that mild learning disability is quite common – estimated to be in the region of 20 per 1000 of the population. These statistics appear to be universal.

In the UK it is estimated that over 1 million people have a learning disability, approximately 2% of the population (Kerr et al, 1996). More males than females are affected, with about one quarter of sufferers under 16 years of age. Twenty-five percent of the population with learning disabilities have profound impairment with additional disabilities. It is also known that people with learning disabilities have an increased prevalence of associated medical problems such as epilepsy which further increases their health care needs (BSDOH, RCSEng 2001).

In Northern Ireland, it is estimated that there are approximately 16,400 with learning disabilities (McConkey et al, 2003) while in Scotland this figure is around 120,000 (Scottish Executive, 2000). It has been suggested that large proportions of this population may have only occasional or short-term contacts with local authorities or health services.

It is also believed that the prevalence of disability will increase with time. This will, at least in part, be due to better survival rates for neonates with disabilities and increased life expectancy for adults (DHSSPS.NI, 2002).

2.3.2 Disability Rights

Until recent years, if an individual with learning disability was subject to exclusion or substandard treatment, there was little they could do about it; the offence of disability discrimination did not exist. This situation has however changed since the Disability Discrimination Act of 1995 (DoH, 1995). Introduced from 1996, the Act now makes it unlawful for a service provider to treat a person with disabilities less favourably for a reason related to their disability, or to have failed to have made reasonable adjustments to the physical features of their premises to overcome physical barriers to access. Barriers to access include both physical obstacles and lack of awareness (Edwards et al, 2002). With the introduction of the Disability Rights Commission (DRC, 2006) the legislation has given individuals with learning

disabilities not only the right to access services, but a means to take action where this is denied.

However, the merits of the Disability Discrimination Act [DDA] (DoH, 1995) are equivocal, with some authorities identifying loopholes which effectively condone continued discrimination in some circumstances; use of terms such as "reasonable" and "justifiable", providing a broad defence. It is noteworthy that no such caveat exists in racial or sexual discrimination laws (Marks, 1999). It is perhaps for this reason that the DDA has been referred to as, "*a masterpiece of ambiguity"* (Johnstone, 2001).

2.3.3 Healthcare Needs

With the closure of long-stay institutions, successive Governments have set out to create a system of delivery of health services as an essential component of community care. It has been acknowledged, however, that;

> *"Significant problems were reported in the reshaping and development of appropriate and accessible primary, specialist and continuing health care services, especially for people with complex or additional physical or mental health care needs"* (DoH, 1999)

So what has gone wrong? Barriers to delivery of a good service have been reported as communication difficulties, the effect of challenging behaviour during

consultations and inadequate consultation time. Lack of knowledge of health needs and diagnostic procedures relating to people with learning disabilities, are also frequently cited barriers (Hogg, 2001). These views are supported by Duff et al (2000) who suggested that the root of the problem for people with learning disabilities lies in the lack of medical training in aspects of care for this group.

2.3.4 Wider Determinants of Health: The transition period

In addition to the issues of access and equality, the difficulties specific to adolescents with learning disabilities must be raised. This population has been loosely defined as individuals in 'the transition period'.

Paediatric dentists have traditionally taken care of many individuals with complex medical needs, including learning disabilities. With improvements in health care, the life span of this population is increasing. This has resulted in many individuals reaching ages where paediatric dentists are no longer willing to treat, but have nowhere to refer on to but adult services (DHSSPS.NI, 2005).

Heslop et al (2002), found that one fifth of young people with learning disabilities left school without a transition plan. Elsewhere it has been noted that young people can experience a decline in service provision when they transfer to adult services (DoH, 2004). It has also been suggested that, young people with the most

complex needs tend to be offered inappropriate segregated adult services (Prime Minister Strategy Unit, 2005).

A small cross sectional sample of 14 – 15 year olds in Northern Ireland revealed high prevalence of disease and highlighted the need for further investigation into the dental health status of this population (DHSSPS.NI, 2005). There would appear to be little recognition of the needs of young people in making the transition from child to adult services. While care for the adolescent interrelates that for children and adults, there is a risk that those discharged from paediatrics services may lose contact with dental services altogether. Those transferred to the adult department often face long waiting lists with little provision for emergency care in the interim.

'Valuing people' (DoH, 2001) sought to address this issue, recognising the lack of co-ordination between the relevant agencies and minimal involvement of the young person themselves. The document referred specifically to the fact that some adolescents are not transferred from children's to adult services with adequate health care plans, resulting in their exclusion from adult services. Furthermore, this is likely to affect young people with severe learning disabilities and complex health needs in particular.

Parents' experiences reflect the typically encountered frustration at this process:

> *"All we got on her sixteenth birthday was, three days later, a letter which says 'You are now over sixteen. You're discharged'".*
>
> *"The children's ward wouldn't accept her because she was over age sixteen, the adult ward wouldn't accept her because she was under eighteen, and so we had a hell-of a-game trying to find a ward for her and in the end she ended up in a geriatric ward for the night".* (DoH, 2001)

Clearly, age alone does not define adulthood, yet it seems to be the criterion used to determine allocation of services. It is therefore debatable how successful more recent 'good practice guides' on the subject of transition will be, such as the Governments' most recent publication "*Healthy lives, brighter futures – the strategy for children and young people's health"* (DoH, 2009), in circumventing this fundamental principle to "minimise health inequalities" by maintaining "continuity of services transition".

2.3.5 Oral Health Needs

It is well recognised that the impact of oral conditions on an individuals' quality of life can be profound (Locker, 1992). Good oral health can improve general health, dignity and self esteem and social integration.

The most common dental problems associated with learning disability are untreated carious lesions and periodontal disease. These problems are not necessarily inherent to the disability but would seem to correspond primarily to dental neglect.

i. Dental Caries

In 1884, Rhodes examined and reported on the dental health of the "insane" by comparing the dentition of inmates of a mental hospital in Cambridge with patients from Addenbrooks. He concluded that tooth quality, relative to other people of similar class, was "good" (cited in Nunn, 1987). Subsequent studies, indeed to present day, have concurred with Rhodes' idea that the prevalence of dental caries in patients with learning disabilities is similar to that found in 'normal' populations (Pool, 1975, Costello, 1988). Indeed, it has been well documented that historically those residing in institutions have had a lower prevalence of caries, probably related to restricted access to a cariogenic diet (Forsberg et al 1985).

Yet, when the individual components of the decayed, missing and filled teeth (DMF) are analysed, the type of treatment offered to this population becomes apparent. High levels of untreated dental caries have been reported by several sources (Costello 1988, Cumella et al 2000, Crowley 2003). Furthermore, the 'missing' component reflects the mainstay of treatments for this group as extractions rather than restorations. It is discouraging that this situation has progressed little since

the 1960's when similar research was reported by Swallow (1966) and Butts (1967) (cited in Nunn, 1987).

ii. Periodontal Disease

There is general agreement that the prevalence of periodontal disease is considerably higher and standards of oral hygiene are significantly poorer, in individuals with learning disabilities (Gizani et el 1997, Nunn 1987, Evans 1991). It has been reported that gingival hyperplasia affects 20% of children with severe learning disabilities (Forsberg, 1985). Studies have also reported that for children with learning disabilities there is an increase in periodontal disease with age, the highest prevalence being found in 16 – 19 year olds (Vigid, 1985). Evidently a large proportion of this group will depend on others for assistance in controlling dental plaque, a task that will only be performed if carers are suitably motivated and capable (Stiefel et al, 1984).

iii Specific Orofacial Complications

Even early studies by Rhodes (1884) led to the conclusion that this group of patients had "ill formed maxillae and over crowding". More recent research regarding skeletal class relationships has been conflicting, with some sources reporting Class III malocclusions while others suggest increased overjets (Tanembaum and Miller 1960, Gullickson 1969, cited in Nunn, 1987). It is estimated that 10% – 20% of those with learning disabilities engage in some form of self inflicted injurious

behaviour. Drooling, bruxism, erosion, rumination and perching are additional problems that may further compromise oral health for this group (Tesini and Fenton, 1994).

iv Down's Syndrome

With an incidence of 1 in 600 births, this group comprises a considerable proportion of individuals with learning disabilities. It is generally accepted that the Down's Syndrome population has an increased prevalence and severity of periodontal disease, compared to those with learning disabilities alone, even when oral hygiene is good (Francis et al, 1991). In contrast to caries, periodontal disease is worse in institutionalised individuals with Down's Syndrome because of lack of time devoted to tooth brushing and the removal of plaque (McIver and Machan, 1979). However, with respect to caries levels in Down's Syndrome individuals, the evidence is conflicting. Some studies have reported lower caries levels in Down's Syndrome (Barnett et al 1986), while those studies with controls for age and number of teeth have reported no difference between individuals with Down's Syndrome and those without (Vigild, 1986). Those in support of the theory of decreased caries in Down's Syndrome individuals have suggested abnormal dental morphology, congenital absence of teeth and delayed eruption as possible hypothesis.

Various other orofacial abnormalities, specific to Down's Syndrome, have been documented; they include macroglossia, bruxism, tongue thrust, enlarged tonsils

and adenoids and a tendency to skeletal Class III based relationships (Allison and Hennequin, 2000).

v Level of Severity of Disease and Unmet Need

Individuals with learning disabilities however must not be viewed as a homogenous group. It has long been recognised that people with mild learning disabilities and those who are more independent have higher caries prevalence, presumably as a result of fewer dietary restrictions (Storhaug and Holst, 1987). This group is also found to have more fillings, fewer extractions and better oral hygiene (Kendall, 1991). Clearly, the relationship between oral disease and dental treatment received is dependant on the patient's ability to understand and comply with the operator (Francis et al, 1991). The situation deteriorates further for those individuals with additional disabilities, particularly physical disabilities (Shapira et al, 1998). Poor motor control, lack of cleansing and food clearance and mouth breathing may all be contributing factors.

With the move towards normalisation and greater independence, new risks regarding oral health have emerged. Those with learning disabilities residing in the community have greater unmet oral health needs and less service contact than those in residential care (Tiller et al, 2001). Yet it is interesting to note that the expectations of people with learning disabilities have been found not to differ from those of the general population;

"*I don't want to lose my teeth…It's pride…I don't want to lose my pride"*

"It makes me look uglier…When my friends see me they run a mile. They always say to me 'don't you ever smile?' and I say, 'I've got nothing to smile about, and if I did, you wouldn't like the state of my teeth anyway'…I never smile". (Cumella et al, 2000)

There is also recognition by those with learning disabilities of the importance of regular dental checkups (DHSSPS.NI, 2005).

2.3.6 Organisational determinants of health care

Do, then, the critics of the DDA have grounds for complaint, or is there simply a resurgence of stigmatisation that has been ongoing throughout the ages? Despite the rhetoric of integration, community care and human rights, it would seem that the quality of dental services for those with learning disabilities has not significantly improved. Whilst historical observations may present an improvement on traditional models of care, they are still far from ideal and the extent to which the needs of people with learning disabilities are being met on their terms, in a climate of acceptance and inclusion, is debatable.

There is clear evidence that all (including dental) health care needs of individuals with learning disabilities are still not being fully met; this group is less likely to

receive regular health checks with their health care providers (eg general medical practitioners) (Band, 1997), it is known that less than 10% of individuals with learning disabilities eat a balanced diet, with a lack of knowledge and choice about healthy eating (Robertson et al, 2000) and 33% fewer adults with learning disabilities receive invitations to mammography than women without learning disabilities (Davies and Duff, 2001). It is little wonder that the Disability Rights Commission 2006, commented that

> "*There is compelling evidence of inequalities in health outcomes between disabled and non disabled people; and evidence of significant problems in access, staff attitudes and quality of service".* (DRC, 2006)

So what are the barriers that prevent people with learning disabilities accessing health services they need? Why has legislation such as the DDA and the White Paper, *Valuing People* (DoH, 2001) not changed the balance of power between professional and service user?

Historically research had reinforced the notion that barriers had the characteristics of physical obstructions. However it became apparent that the idea of barriers and the concept of access represented two sides of the same coin (Freeman, 2000). The term barrier was to be considered as a means of examining access by Cohen in 1987, when she reported on the FDI's classification of "*accessibility factors*". These factors existed within a three-level structure, with accessibility being reflected at

the patient, health professional and Government/society level (Table (iii)). Thus, ironically, the barriers that prevent people with learning disabilities gaining access to dental care are at least partly due to the very professionals that are supposed to helping them. For the purposes of this survey, only those accessibility factors within the 'dental professional' level of the framework will investigated.

Table (iii): FDI's classification of accessibility factors

Accessibility Factors	
1. ***Patient factors***	Lack of perceived need, anxiety and fear, financial considerations and lack of access.
2. Dental professional factors	Inappropriate manpower resources, uneven geographical distribution, training inappropriate to changing needs and demands and insufficient sensitivity to patient's attitudes and needs.
3. Government/society factors	Insufficient public support of attitudes conducive to health, inadequate oral health care facilities, inadequate oral health manpower and insufficient support for research.

It would therefore seem that the complexity of dentists' decisions to see patients with learning disabilities is based on financial, geographical, attitudinal and educational factors.

2.4 Accessibility Factors – The dental professional

2.4.1 Inappropriate Manpower Resources

i Organisation of Care

The impetus to supporting individuals with learning disabilities accessing mainstream healthcare, clearly originates from the philosophies of normalisation over the past two decades. However, there have been concerns regarding the capacity of community based services to adequately meet the needs of those with learning disabilities (DoH, 2001). Meehan et al (1995), for example, found that 106 of 191 adults with learning disabilities living in the community were examined and found to have at least one unattended but treatable medical condition. Since it has been suggested that the prevalence of people with learning disabilities will increase with improved survival rates for neonates and more children surviving into adulthood (DHSSPS.NI, 2002), there is no doubt that there will be a need for involvement of increased numbers of dentists in the provision of dental services for this burgeoning population.

The 1987 White Paper *"Promoting Better Health*" stated that the

> *"CDS would in future provide treatment in the main for children and adults who experienced difficulty in obtaining dental treatment from GDP's".*
>
> (DoH, 1987)

This was further developed with the publication of *"Improving NHS Dentistry"* (1994), whereby patients falling outside the remit of the "core service" of treatment provided by the GDS, were to have their needs catered for by the CDS (Freeman and Adams, 1997).

Concerns were raised within the CDS that this 'safety-net' responsibility, in addition to their role as providers of care for special needs patients, would reduce access to care for special needs patients because of limited resources.

Subsequent research concluded that both the CDS and the GDS were providing primary dental care for patients with special needs (the definition to include those with learning disabilities). However significantly larger proportions of patients form a wider variety of special needs groups were treated by the CDS compared with the GDS (Freeman and Adams, 1997), with the CDS also providing more domiciliary care for this population. Thus, a continuum of service provision was said to have existed.

ii. Institutional vs. Community Care

It soon became evident that with the sustained shift to community living from the institutional setting, came a simultaneous shift in the dental treatment provided. Stanfield et al (2003) found that 24% of patients with learning disabilities had not

received a dental examination within the previous year of community based living. This was despite knowledge that they might be able to cope with an examination, as all had received dental care when institutionalised. Of further concern was the finding that individuals received significantly less operative dental care in the community compared with their care as inpatients, which was more likely to involve professional oral cleaning (therefore not wholly reliant on carers) and restorative procedures/extractions under local anaesthetic.

The Mencap Health Report *"Health for All"* (1998) made reference to the problems experienced by people with learning disabilities in obtaining dental services;

> "*A two year wait for treatment by which time seven teeth needed to be removed".* (Band, 2008)

Indeed in Northern Ireland, in the Eastern Health and Social Services Board (EHSSB), the waiting time for assessment in 2005 for special needs patients (including adolescents with learning disabilities) was estimated to be 2 – 3 years, with a further delay thereafter for treatment. Unfortunately this situation has culminated in undesirable media attention, with hasty management of those in 'absolute crisis' – hardly a long term solution to a spiralling problem of inadequate resources. This situation compares unfavourably with Highland Health Board in Scotland, where patients up to 16 years of age have an assessment waiting time of just 8 weeks with a maximum delay of no longer than 18 weeks from assessment to treatment.

So why then are so many individuals with learning disabilities slipping through the 'safety net' by either disappearing anonymously into the community or else being known to dental services but existing with unmet treatment need? (see Section 2.3.5).

iii. Financial Implications

Studies have shown that dentists working within the GDS would appear willing, at least in principle, to provide treatment with individuals with learning disabilities. Freeman and Adams (1991) found that 96% of GDS practices in London boroughs were willing to accept special needs clients who were exempt from fees, while in Merseyside over 90% of practices reported treating patients with disabilities, most were also willing to treat more disabled patients (Edwards et al, 2002).

Yet there is a belief in the UK that less than half of GDP's are providing NHS care. The move towards private practice has meant that 'difficult cases' are more likely to be passed on elsewhere (DoH, 2000). There can be no doubt that for a proportion of individuals with learning disabilities, particularly those with severe disabilities and complex medical needs, treatment under general anaesthetic will remain the preferred option. In one study over a 12 year period (Campbell, 2003), it was found that 75% of long stay residents with a learning disability needed a general anaesthetic for the purposes of providing their dental treatment. But is general

anaesthesia, as an adjunct to dental treatment, used too frequently among people with learning disabilities, given the inherent risk in its use and the high cost implications? Some sources (Holland et al, 1996) have suggested that this figure should more accurately approximate to 20%. This would suggest that the majority of patients with disabilities would fall into the primary care category and treatment should be provided in this setting. This was supported by the findings of Holland et al's previous study in 1990, when they noted that in 189 patients with disabilities, treatment was completed for 130 patients by final year undergraduate dental students, junior hospital staff and a health board officer working in a rural clinic. This supports the view that the majority of patients with learning disabilities can be treated successfully in the primary dental care under local anaesthetic, with or with out inhalation sedation, by dental practitioners with no specialist training (Pool, 1982). Interestingly, the increased frequency of dental treatment requiring general anaesthesia in the primary rather than secondary dental care, does raise the possibility that community based general dental practitioners may wish to avoid providing dental treatment for this group to circumvent any real or perceived behavioural difficulties (Stanfield et al, 1993).

Is referral for general anaesthetic simply, therefore, then the 'easy option' for those in primary care, or are there other factors influencing the onward referral of patients with learning disabilities to secondary services?

For many dentists working within the GDS, the perceived time and effort required to provide care for people with learning disability, creates a financial disincentive (Stiefel et al, 1981). The present NHS fee scale is not commensurate with the management of complex medical histories and the need for longer and/or more frequent appointments related to the real or perceived patient behavioural problems (Edwards et al, 2002). Furthermore, while the situation of poor physical access to surgeries, reported as a barrier to care by Wilson (1992) and Ferguson (1991), may have improved with the introduction of the DDA, dentists have reported that financial influences may limit these improvements, as lack of access to development grants for dental practices can make it difficult to address the remaining problems (Edwards et al, 2002).

Poor remuneration is also cited as the reason for inadequate domiciliary care services. In the UK an NHS dentist, on average, provides home care for only 2.9 patients per month (Burke et al, 1995). Although it has been noted that larger proportions of CDS practices compared with the GDS, provide domiciliary dental care (Freeman and Adams, 1997), senior dental officers and family carers alike have commented on the inequity of accessing 'out of hours' dental care (DHSSPS.NI, 2005). However, in their defence, GDP's have reported the lack of availability of domiciliary equipment (Edward et al, 2002[1]) and inexperience in this area of care (DHSSPS.NI, 2005) as further barriers. These influences serve to reinforce the view that domiciliary dental care is often not a viable financial proposition. These financial issues clearly relate to the need for speed and efficiency, linked to the

concept of fee for item of service. So can a salary or sessional fee overcome this problem?

iv Salaried Dental Services

In a bid to address the manpower issues which impinge on access to NHS dentistry for those unable to access care, the primary dental care services were reviewed and restructured in Scotland (Scottish Executive, 2006). The resulting Salaried Dental Services (SDS) was formed through merging the CDS and salaried GDS services already in existence and led to NHS Highland having the greatest number of salaried dental locations compared with other regions of Scotland. The Taylor Report (2006), as this document came to be referred, clarified the roles of the SDS as follows:

- Provide care for people with special needs
- Complement the current GDS and specialist services, especially in remote and rural areas
- Make greater use of specialists
- Make greater use of professionals complementary to dentistry, both clinically and for a public health role.

The salaried General Dental Services aimed to improve registration and access for patients in remote and rural areas (Collins, 2002). It has been reported however,

that the dental services delivered by a salaried workforce can be costly in relation to the volume of clinical activity produced, although these costs can be offset by deployment of auxiliary staff (Downer et al, 2006). Indeed the DHSSPS.NI (2005), in recognition of shortage of hygienists available in Northern Ireland to provide a service for people with learning disabilities, has recommended a reversal of this situation. Likewise, Sturing and Hinds (1983, cited in Holland and O'Mullane 1990) suggested value in making use of the skills of other health care professionals in the dental care of patients with learning disabilities; for example, occupational therapists in the area of oral hygiene and dieticians regarding caries management.

In the interim in NI, the CDS will continue with its' duty to provide care for all those people who are unable or unwilling to obtain their care through the GDS 'core services'. The CDS however has suffered significant staff reduction, to the extent that numbers of clinical dental officers have been cut from 1092 in 1985 to 649 by 1994 (Nunn, 2000). This problem has been exacerbated by the national acute shortage of NHS dental manpower in large areas of the UK. Nevertheless, the British Dental Association have developed and conducted a field trial of a case mix model to measure the complexity of specific patient factors which increase the time taken and costs of treatment. For each episode of care, the case mix model assesses the following on a four point scale: 'ability to communicate', 'ability to co-operate', 'medical status', 'oral risk factors', 'access to oral care', and 'legal and ethical barriers to care'. The tool has been piloted in NHS Highland (Hally and Freeman, 2009), where the potential of the model as a tool to help practitioners

and commissioners gain greater understanding of the services provided, has been demonstrated. It is anticipated that in this manner, appropriate deployment of resources for the cost of treating special care patients will be ensured (Bateman et al, 2010).

So what impact has this restructuring of primary dental care services had on accessibility of dental care for individuals with learning disabilities and primary care practitioners' willingness to treat this client group? Has removal of the financial disincentives in NHSH led to a positive outcome in the unmet treatment needs for those with learning disabilities in this region of Scotland, compared with an area such as EHSSB in Northern Ireland, where no such comprehensive primary care system, devoid of financial pressure, exists?

v. Role of the Specialist

There is an unquestionable need for increased willingness amongst a greater number of general dental practitioners to provide services for a growing array of individuals with learning disabilities. While the CDS and GDS provide a broad spectrum of services, general dental practitioners have reported low confidence in their ability to manage patient's disabilities and complex medical problems (Oliver and Nunn, 1996). Similarly, Shanley and Guest (1995), in their paper on stigmatisation, highlighted that nurses' own senses of insecurity in not knowing how to cope with an individual with learning disabilities, may adversely affect their

relationship with the patient. This can lead to the patient being avoided as nurses find themselves unable to determine how to communicate with that individual. This may be a pivotal factor in whether care is provided or what type of care is offered.

It is expected that with the recent establishment of Special Care Dentistry as a specialty, there should be improved access primary to care (Kiyak, 1988). Recognition of the specialty will allow the development of a structured workforce to help meet the needs of people with learning disabilities, through integrated care pathways developed via liaison with all members of the patients' care team. In this respect, competence in the provision of oral healthcare to people with learning disability would flourish, through research, consistent advice and professional training.

But are there negative aspects to this concept? First, does the establishment of this specialty serve to reinforce the sentiments 'let someone else do it' or 'it is beyond my expertise'. Secondly, would enhancing broad based abilities of general practitioners to provide care, augmented by improved financial remuneration, be a more realistic option?

2.4.2 Uneven Geographical Distribution

i Demographics

EHSSB is a mainly urban region of Northern Ireland encompassing Belfast, and covering an area of around 1,750 km² a population of approximately 665,000 are served by approximately 383 dentists working across general practice and the Community Dental Services.

In contrast, NHS Highland catchment area comprises the largest and most sparsely populated part of the UK, exacerbated by difficult terrain, rugged coastline and limited internal transport and communication infrastructure. The area covers 32,500 km² with the geographical nature of the region presenting particular challenges for the efficient and effective delivery of healthcare services. In 2005, a national framework for service change *"Building a Health Service Fit for the Future"* known as the *Kerr Report*, was published. This report recognised the particular challenges facing rural communities in Scotland, including access to services and transport issues. NHS Highland serves a population of approximately 209,000; with 154 NHS dentists working across independent NHS practice and the Salaried Dental Service.

ii. Transport

The inability to get to a dental surgery is a major barrier to dental care for wheelchair users or housebound patients with complex medical histories and has been reported by several authors (Stiefel, 1979, Pool, 1981). There may be significant costs in terms of physical effort, emotional effort, time and financial outlay. It must be remembered that additional costs will be incurred by the

'minders' who may also need to attend with patients. Obviously, these costs with become more significant if a service is provided in a rural area, as the distances travelled with be greater than for those availing of a service within an urban catchment area. Centralised out of hours emergency services may be even more difficult to access, as the use of taxis may be the only viable option. These issues may account for the high rates of failed attendances and failure to complete courses of treatment (Pugh 2000, cited in Manthorpe 2007).

2.4.3 Inappropriate Training to Changing Needs and Demands

i. Undergraduate Education

The role of dental education in preparing graduates to treat patients with learning disabilities has been explored for several decades. Efforts to improve undergraduate education in this context became prominent with the introduction in the United States in 1973 of the Robert Wood Johnston Foundation (cited in Casamassimo, 1983).

The Robert Wood Johnston Foundation programme provided large grants to 11 schools over a 4 year period, the overall objective being to provide specific training eventually leading to the improvement of accessibility of dental care to individuals with "handicapping conditions" (Campbell and McCaslin, 1983). The concept was based on the early observations that appropriate training had a direct influence on student's willingness and ability to treat 'handicapped' patients [(Needham, 1968; Moonsbrucker and Giddon, 1966) cited in Lee and Sonis, 1983]. More recent

studies with dental students (Wolff et al 2004, Smith et al 2006, O'Donnell 1993, Lee and Sonis 1983, Bedi et al 1986, Block and Walken 1980), dental hygiene students (Bickley 1990, Schuchman, 1984) and GDPs (Casamassimo et al 2004, Bedi et al 2001, Sota Roja and Cushings 1992) have reiterated earlier findings that inadequate 'exposure' (including didactic teaching, observation of senior colleagues and hands on experience), was correlated with a lack of knowledge and confidence, ultimately resulting in reluctance to treat individuals with learning disabilities. However, while the overall effect of educational programmes such as the Robert Wood Johnston Foundation was reported to be positive, it has also been suggested that the results with regard to actual treatment of patients with learning disability can be limited and indeed may even have a negative effect (Waldman, 2005, Casamassimo, 1983).

The approach of didactic teaching programmes in particular has been criticised; in Casamassimo's (1983) opinion these provide too much information that, if retained, serves mainly to confuse. Casamassimo (1983) has further suggested that educational programmes in the care of special needs patients do not necessary increase the number of dentists prepared to care for these patients, but rather serves to reinforce the resolve of those practitioners who already have favourable intentions. Perhaps the conflicting results of studies since 1973 presents a picture of the failure of the undergraduate curricula to embrace the emphasis of care from the institutional to community setting.

However, the need for appropriate contact with patients with learning disabilities must not be dismissed. Patient contact with nursing students has been shown to facilitate development of more positive attitudes (Murray and Chambers, 1991). Perhaps it is more worthwhile to consider the reverse scenario: poor attitudes towards people with learning disabilities have been demonstrated to result in unmet need (Slevin and Sines, 1996). Furthermore, stigmatising attitudes among staff can adversely affect health care for people with learning disabilities.

ii. Attitudes of Dental Students

The impact of dental education on shaping attitudes towards people with learning disabilities has long been recognised (Scholle, 1979, Nunn and Murray 1988, Kinne and Stiefel 1979), with acceptance that negative attitudes towards patients with learning disabilities is correlated with unwillingness to provide care. In general, healthcare professionals hold more negative attitudes to people with disabilities than might be expected (Chubon, 1982). Clearly, these findings have significant ramifications for determining outcome and access to care.

Studies of the effects of education upon attitudes towards people with disabilities, show that attitudes of dental students can change throughout the course of their training. Results however, have been inconsistent. Numerous studies have indicated that fear and anxiety due to lack of experience in treating patients with learning disabilities, has been overcome through participation in extra mural programmes (Block and Walken, 1980, Kinne and Stiefel 1979, Campbell and

McCaslin, 1983) resulting in positive attitudes and subsequent willingness to provide care for this group in their future practice. This, however, contrasted with the findings of Stiff and Phipps (1964) who proposed that attitudes actually deteriorated in a group of students exposed to special needs patients. They concluded that unless the experience is positive, it can be counter productive leading to frustration and disillusionment. This process may be exacerbated by the increase in cynicism known to occur as dental students progress in their education (Coyle et al, 2004). Similarly, O'Donnell (1993) and Coyle et al (2004) have found the attitudes of dental students towards patients with learning disabilities to be markedly poorer than those of a controlled group and a group of undergraduate social policy students respectively.

iii. Postgraduate Education

Dentists have admitted to feelings of uncertainty and incompetence while treating patients with learning disabilities and concerns over lack of experience are important issues in their decision whether or not to provide care. This was demonstrated by the results of Freeman and Adams (1991) who found that those dentists who had previous experience of treating special needs patients and carrying out domiciliary dental care, intended to provide care for this group. Furthermore, these dentists appeared to have more positive attitudes and were able to assess both the relevance and reality of their own belief in the light of their previous working behaviours. Likewise, Sota Roja and Cushings (1992), reported dentists concerns about competence, confidence, interpersonal skills and

organisational difficulties, with respect to treatment of people with learning disabilities. Seventy percent believed there was a need for education and training of dentists, with postgraduate training being the most highly favoured option. In service training, observation of other dentists (particularly experienced clinicians) and continuing education courses, were opportunities that dentists wished to avail of. It would appear that there is certainly demand and motivation to gaining further training and develop skills. In an earlier survey conducted by the FDI on "Oral Health of the Handicapped" (1989), less than half of the 54 member countries had any provision for undergraduate or postgraduate training in the care of people with impairments. Yet nearly three quarters of those responding, said that there were insufficient post graduate seminars in the subject. Similarly, Loppeky and Sigal (2006) in their study of general and paediatric dentists in Ontario, found that significant numbers of dentists would be more motivated to provide care to patients with special care needs if they had additional training.

Furthermore, the effects of postgraduate training can be marked. Edwards et al (2002[2]), reported that staff who had been on disability awareness training were more willing to consider a wider range of changes to their practice, as opposed to just physical barriers, compared with staff who had not yet had training.

The question must therefore be asked; why do more opportunities in postgraduate education not exist, when there is such enthusiasm for a broader training?

iv.Communicaton and Consent

Communication is at the very core of the dentist patient interaction. It has been said that:

> "*Communication makes the critical difference between isolation and social connectedness, dependence and independence, withdrawal and fulfilment"*
>
> (Jordan et al, 1993)

Likewise, in recent years, the language of community care has called for professionals to develop a greater range of communication skills and interpersonal abilities, to help aid service users. However, despite much emphasis on the matter, in practice it seems that dentists still consider communication to be a problem (Davies et al, 1988). From the perspective of the patient, the limited non verbal communication of health professionals, fails to support and extend the service users communication (Clegg et al, 1991).

Cumella et al (2000) reinforced this message, in their study of oral care needs of a group of patients with learning disabilities who had lost contact with the CDS. Participants of the study expressed a particular need for a good relationship with their dentist who ideally should also have personal skills in relating to people with a

learning disability. Common elements in their responses were ‘tolerant’, ‘patient’, ‘communicate with people’ and ‘valuing’.

The last decade has seen legislation such as the Children (Scotland) Act 1995, along with its parallel legislation the Children (Northern Ireland) Order 1995 and the Children Act 1989, emphasis the importance of involving disabled adults and children in their own assessments of need, planning for their own futures and taking account of their views about the services they receive. The Children Act goes so far as to assert that:

> *“Even children with severe learning disabilities are or very limited expressive language can communicate preferences if they are asked in the right way by people who understand their needs and have the relevant skills to listen to them”.* (DoH, 1989)

The challenge to health care professionals is to find creative ways to enable adequate modes of communication to take place (Ferris-Taylor, 2007). Understanding and misunderstanding are obviously important areas to consider alongside the issue of consent. People with a learning disability are increasingly being encouraged to take a more active role in decisions about their treatment (Arscott et al 1999). The assessment of competence is the key issue for the adolescent over 16 years of age, when the patient is refusing or appears to be refusing, treatment.

The more dentists can learn about the capacity for decision making and levels of understanding, the better the interests of both patient and dental professional will be protected. In the light of such concerns, Allen and Tynan (2000), highlighted need for training in effective communication and behaviour management thereby improving staff knowledge and confidence in the workplace.

2.4.4 Insufficient Sensitivity to Patients Attitudes and Needs

i. Perception of the Need for Care

There would appear to be disparities between dentists' perceptions of the necessity for dental treatment and the views of the parents/carers/patient. A study by Davies et al (1988) found that while parents of people with learning disabilities believed that regular attendance was necessary for maintenance of function (30%), clear speech (20%) and aesthetics (43%), significantly fewer dentists offered these reasons, with only one dentist out of 30 interviewed mentioning function and aesthetics and none at all considering that clear speech for those with learning disabilities, were important issues.

Consider, also, the views of a parent who has a child with cerebral palsy;

> *"The cosmetic issue of dental hygiene has always been important to us; when Alexander was young an educational psychologist told us that because he was a good looking, responsive child, people would be attracted to him*

> *and this would be a great benefit. This has proved to be true. We have noticed the problem other, older children with cerebral palsy have with gaps, crooked, broken or discoloured teeth and the way people shun them or avoid contact."* (Nunn, 2000)

These sentiments perhaps encapsulate the essence of the oral health strategy group (DoH, 1994) and their definition of oral health as:

> *"A standard of health of the oral and related tissues which enables an individual to eat, speak and socialise without active disease, discomfort and embarrassment and which contributes to general well being."*
>
> (DoH, 1994)

It seems that for individuals with learning disabilities, their dental aspirations are frequently ignored. In a survey of people with learning disabilities (DHSSPS.NI, 2005) participants in a focus group articulated the importance they attached to aesthetics and attractiveness and their revulsion at the concept of denture wearing. This group also placed dental health high on their list of priorities. Furthermore, the same individuals wrote the following comments about their previous experiences of dental appointments,

> "*we get treated like toddlers…like a five year old"..; "wake up – I'm an adult"..;*

"…irritating when they just shout" (DHSSPS.NI, 2005)

This work from Northern Ireland (DHSSPS.NI, 2005) supports that of Pratelli and Gelbier (1998). They (Pratelli and Gelbier, 1998) reported, disappointingly, that a lack of sensitivity on the part of some professionals in communication is still evident;

"*they had expertise with the teeth but…they didn't talk directly to the patient".* (Pratelli and Gelbier, 1998)

These situations reflect the notion of being treated as a non person. In recognition of such attitudes, Wasinger (1986) in his personal reflections of his experiences of treating disabled patients, concluded the following;

1. *A nice smile is important for a good self image and a good self image is important for health.*

2. Inside each person with a handicapping condition lies a fully functioning whole person with a strong need to be treated as a whole person.

3. An impaired physical body [or indeed mind], has nothing to do with ambition or the cognitive process. (Wasinger, 1986)

It seems that dentist 'expert' assessments of the 'needs' of the patient with learning disabilities are based on objective evaluations of 'essential requirements'. The term 'want' tends to be treated as a subjective desire, as is the case for cosmetic treatment, which may be perceived as a 'dispensable luxury'.

ii. Medical vs. Social Model of Disability

The traditional way to view disability of any nature is to see it simply as a medical problem. Medicine (and Dentistry's) drive to make normal that which it considers to be pathological and dysfunctional, claims to be value neutral. Yet in practice, as exemplified by the previous observations of patients with learning disabilities and parents of children with learning disabilities alike, medicine contains a series of normative assumptions about value, beauty and function which influences its practices (Marks, 1999). This medical model draws upon Cartesian principles, and by this approach disability and the ensuing problems arise as the result of impairment. In this manner, the disabled person becomes the centre of attention. The focus is on changing the individual, usually through the medical modification of their impairments (Figure 1).

Figure 1 The medical model of disability.

Source: Employability in the North? A good business practice for North East employers on the employment of disabled people. By David Barker, 1998. Disability North.

Patients are expected to gratefully accept the treatment are offered and are not seen as having a role in decision making. Such passivity may be neither necessary nor appropriate. Additionally, the medical model presents the environment as neutral and stable. The onus is on the individual to adapt, adopt coping strategies and limit their own hopes and ambitions (Barnes, 1999). It may be suggested, therefore, that the medical model is the philosophy of the undergraduate dental

curriculum (The First Five Years, 2002) and is indeed the basis of the DDA (DoH, 1995) which has come under criticism in part for this reason.

An alternative approach is the social model of disability, described by a number of disabled activists and scholars within the UK, such as Oliver (1990). This model locates disability not in an impaired or malfunctioning body, but in an excluding and oppressive social environment. This model argues that the restrictions imposed on disabled people are not the inevitable consequence of their impairment, but are a product of a social environment which fails to include them (Figure 2). Impairment in this context is thus defined as the limitation in a persons physical, mental or sensory functioning, which only becomes salient and disabling in specific settings (such as the inability of the general population to use sign language). Critics of the social model accuse it of failing to acknowledge the importance of the body and impairment in understanding disability (Crow 1996), thereby losing site of the inter-relationship between the social, psychological and biological aspects of disability. Nonetheless, it is interesting to note that the social model forms the core of the undergraduate curriculum for social policy. Undergraduate students in this discipline have been found to have more positive attitudes towards people with learning disabilities than do undergraduate dental students, for whom the medical model is central to teaching (Coyle et al 2004).

Figure 2 The social model of disability.

Source: Employability in the North? A good business practice for North East employers on the employment of disabled people. By David Barker, 1998. Disability North.

Whatever the criticisms of the social model, there can be no doubt that it enables traditional assumptions about who has been 'problem' to be addressed. As the social inclusion agenda for people with learning disabilities gains momentum, these philosophies will need to be considered with regard to the needs and sensitivities of the patient.

2.5 Conclusions

Individuals with learning disabilities, particularly adolescents, have more unmet health care needs than the general population, but yet are subject to more barriers in accessing health services. Despite numerous Government White Papers and initiatives, much remains to be done to improve access to services. This will include addressing not just the attitudes which are firmly rooted in the past, but also the issues of today; manpower resources, uneven geographical distribution, inappropriate training and insufficient sensitivity to patients attitudes and needs.

The philosophy of normalisation has been very influential in the development and delivery of services to people with learning disabilities over the past three decades, including the shift from institutionalised to community care. However, the idea that people with learning disabilities do not need services that are any different from the rest of the population can result in a shift to no health care service provision or healthcare services which are inappropriate for their needs (Cooke, 1997). This lack of understanding is a recurrent theme throughout the literature. Yet what there is a paucity of in the literature is evidence of research on the effect of health professionals' knowledge of, or attitudes towards, people with learning disabilities on their access to healthcare, or how to promote positive attitudes and practices when working with this patient group. This issue warrants further investigation.

This proposition has particular relevance for the oral health care of adolescents with learning disability. Despite the Government initiatives, adolescents with learning disabilities can slip through the 'net' and as a consequence receive little or no dental care. It has been suggested that an approach which includes, in the first instance, and examination of dentists' attitudes, knowledge and working practices, as encompassed in Cohen's (1987) accessibility factors, might assist in understanding general dental practitioners' willingness to treat adolescents with learning disabilities in primary dental care.

3.0 Aims and Objectives

3.1 Aim of the survey

3.2 Objectives

3.0 Aims and Objectives

3.1 Aim of the survey

The aim of this study was to examine primary dental care practitioners' willingness to treat adolescents with learning disability (LD) in two contrasting areas of Northern Ireland (NI) and Scotland using Cohen's accessibility 'dental health professional' factors (Cohen, 1987).

3.2 Objectives

- To compare the demography of dentists working in primary care in the health boards of Eastern Health and Social Services Health Board (EHSSB) in NI and NHS Highlands (NHSH), Scotland.
- To examine the undergraduate experiences of dentists by demography, area of work, practice type and service type.
- To examine the postgraduate experiences of dentists by demography, area of work, practice type and service type.
- To examine dentists' knowledge about LD and its management by demography, area of work, practice type and service type.
- To examine service provision for those with LD of dentists by demography, area of work, practice type and service type.
- To examine dentists' attitudes and intentions to treat adolescents with LD by area of work, practice type and service type.

- To examine the contribution of undergraduate training, underlying knowledge and social and clinical attitudes associated upon the dentists' willingness to treat adolescents with LD.

4.0 Method

4.1 The sample

4.2 The questionnaire

4.3 Analysis of data

4.0 Method

4.1 The sample

4.1.1 NHS health boards

Two NHS Health Boards were selected to take part. These were first the Eastern Health and Social Services Board [EHSSB], Belfast Northern Ireland and secondly, NHS Highland [NHSH], Inverness, Scotland. These two Health Board regions were specifically selected in order to operationalise Cohen's (1987) accessibility factors with regard to:

- geographical distribution of dental services:
    - EHSSB: predominantly an urban region with a mean drive time of
    - NHSH: a remote and rural health board with the mean drive time to access dental services being 120 minutes.
- provision of NHS care:
    - EHSSB: predominately NHS orientated general dental service for patients.
    - NHSH: a predominately private practice orientated GDS.
    - NHS dental care is mainly provided by the salaried dental service (SDS).
- the influence of reimbursement for care
    - EHSSB and NHSH: dentists employed within the independent GDS sector, worked under both private and NHS schemes were included in order to determine the influence of reimbursement for care.

4.1.2 Dental practitioners

A non-probability convenience sample (Hulley et al, 2001) of all dentists working in primary dental care in the EHSSB (n= 390) and NHSH (n=147) were invited to take part in the survey. Contact details of dentists were obtained from the Central Services Agency, Belfast, and from NHS Highland.

4.1.3 Ethical considerations

A protocol was provided to the NHS Research Ethics. There view was the study was essentially an audit of current practices. They advised that ethical approval was not required (Appendix 10.1). Clinical governance committees of the EHSSB and NHS were contacted and permission granted to conduct the survey in the health boards. Dentists were informed of the survey and were requested to read the information sheets and complete a consent form on receipt of the questionnaire documents (Appendix 10.1).

4.2 The questionnaire

The aim of the questionnaire was to assess the dentists' knowledge, attitudes and treatment behaviours, with respect to the provision of dental care for adolescents with LD in their practices. The questionnaire was of a self-completed format and consisted of 4 sections (Appendix 10.2).

- Section 1: Examined the demographic profile of the participant. The questions inquired of the participants' age, gender, university attended, higher qualifications, region of work and type of practice. This section also included specific questions regarding the physical access to the dental surgeries, provision of inhalation and intravenous sedation, emergency care and access to sedation and emergency dental services.

- Section 2: Examined the dentists' previous experience of undergraduate and postgraduate training as well as the perceived need for further postgraduate training in the dental care for individuals with LD. Questions pertaining to the practitioners' confidence as treatment providers were of a 7-point Likert scale format. Scores ranged from 1 (no confidence) to 7 completely confident. Similarly, questions inquiring of the practitioners' intention to treat adolescents with LD and their experience of stress were also of a 7-point Likert scale formats. Scores ranged from 1 (not at all) to 7 (yes definitely). A short series of knowledge questions aimed to discover the practitioners existing knowledge about the prevalence of LD and appropriate provision of care for individuals with LD. The source of correctness of the answers was obtained from Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of people with Learning Disabilities (RCS England, 2001) and the Disability Discrimination Act (DoH, 1995). This set of questions was of a true/false format, with correct answers scoring one and incorrect answers scoring zero.

- Section 3: Examined the dentists' practice routines and patterns of care including their willingness to provide care. The dentists were asked to state the numbers of patients with LD assessed and/or treated, the range of treatment provided and referral behaviours, for example to whom and where patients with LD were sent for treatment.

- Section 4: Comprised of two attitudinal scales. It was desirable that an instrument to measure attitudes would be easily administered and scored, provide reliable and valid results and be standardised among different populations. The attitudinal scales described by Bedi et al (2000) and Coyle et al (2004) are two such instruments. All of the items in Section 4 were of a 5-point Likert scale format ranging from strongly disagree (scoring 1) to strongly agree (scoring 5).

Scale 1: The first scale, composed of twenty items (Bedi et al 2000) to determine underlying reasons why dental personnel might not feel able or feel it appropriate to treat individuals with LD. The items deal specifically with patients with LD in the dental setting. For example, "Aesthetic dental treatment is as important for people with a learning disability as it is for other people".

Scoring of Scale 1: Several items were recorded to ensure that for all items a high score indicated a positive attitude towards people with LD and a low score indicated a negative attitude, as shown below in (a) and (b);

(a)Scoring of responses to questions 1, 2, 6, 7, 9, 11, 12, 15, 16, 19

Strongly agree	**5**
Agree	**4**
Neither/nor	**3**
Disagree	**2**
Strongly disagree	**1**

(a) Scoring of responses to questions 3, 4, 5, 8, 10, 13, 14, 17, 18, 20

Strongly agree	**1**
Agree	**2**
Neither/nor	**3**
Disagree	**4**
Strongly disagree	**5**

Thus it was possible to create a total score for each participant by summing responses to the twenty items in Scale 1. This gave a range of scores from 20 to 100, with a higher score representing a more positive attitude to providing dental treatment for individuals with LD.

Scale 2: The second scale, composed of twenty-four items, concerned general attitudes towards individuals with LD in the social setting. This scale has been used

previously to determine attitudes of dental students towards people with LD (Coyle et al, 2004). It has been shown to have good reliability and validity.

Scoring of Scale 2: The twenty-four items for the second attitudinal scale also used a five point Likert scale as previously, and was recoded as shown below in (c) and (d);

(c)Scoring of responses to questions 2, 5, 6, 10, 12, 14, 15, 20, 21

Strongly agree	**5**
Agree	**4**
Neither/nor	**3**
Disagree	**2**
Strongly disagree	**1**

(d)Scoring of responses to questions 1, 3, 4, 7, 8, 9, 11, 13, 16, 17, 18, 19, 22, 23, 24

Strongly agree	**1**
Agree	**2**
Neither/nor	**3**
Disagree	**4**
Strongly disagree	**5**

A total score was then obtained as a measure of the dentists' general attitude towards those with LD. The possible range of scores was between 24 and 120. A high score demonstrate a positive social attitude towards individuals with LD.

4.2.1 Piloting of the questionnaire

The questionnaire was designed for completion within five to ten minutes. A pilot was undertaken with dentists working within the GDS and CDS. Several questions were then modified to provide ease of answering and clarification.

4.2.2 Administration of questionnaires

The questionnaire was posted to all dentists working in primary care in EHSSB (n= 390) and NHSN (n=147), with a covering letter providing information on the survey and requesting their consent to participate. A stamped address envelope was provided. A second questionnaire was administered two months later to non-responders. . A third and final follow-up of dentists in EHSSB was completed six months later.

4.3 Analysis of data

The questionnaires were scored and coded as described. The statistical analysis of the data was by the use of the software package SPSS version 15. A dropout analysis was undertaken. Comparison between group means was by t-tests and

ANOVA. The post-hoc Scheffe test was used to determine significant differences between groups. Chi-squared analysis and correlation analysis were also conducted. A principle component factor analysis was carried out to identify any factors underlying participants' responses to the two attitudinal scales. All statistical tests were conducted with α at 0.05.

Hierarchical regression was an option to analyse the key variables involved in this study. Of prime importance was to identify an approach to enable a clear analysis of predictors of willingness to treat. A related technique to hierarchical regression known as path analysis was employed as it strongly demands the researcher to specify with clarity the model or framework of variables adopted to assist in the prediction of the dependent variable – in this case: willingness to treat. The model is specified as a series of boxes to denote the variables and arrows to indicate the possible direction of influence (Kline, 1998). Although the use of arrows is controversial as it implies direction of causality, it is recognised that these are only indicative and that there are many alternative models that could have been fitted. However the clarity of the exposition of the model attracted this researcher to persevere with this method and also enabled a presentation that would act as a 'short-hand' to communicate the possible relationships between the variables of interest.

The software package AMOS17 was used for analysis purposes (Arbuckle, 2008). Raw data of scale measures were loaded into the package via a 'diagrammer' which made the specification easy to enter and modifications efficiently implemented. The package enables maximum likelihood estimation and gives warnings if the models to be fitted cannot be 'identified' (i.e. too many unknowns). The package provides a chi-square value with its degrees of freedom. A *p* value can be obtained. For the purposes of this analysis the *p* value should be as high as possible. The interpretation of this value is as follows. Should the model closely fit the date then the chi-square will be small and the probability of there being no discrepancy between the data and model is high. A number of fit indices are available that have conventional values to demonstrate a good fit of the data to the investigator's specified model. The indices chosen were the Comparative Fit Index (CFI, values higher than 0.95 regarded as excellent fit), the Tucker-Lewis Index (TLI, values higher than 0.95 regarded as excellent fit), and a test of parsimony – the Root Mean Square Error of Approximation (RMSEA, values less than 0.05 regarded as excellent fit) (Hu & Bentler, 1999) .

5.0 Results

5.1 The sample

5.2 Demographic profile

5.3 Dental education: training in special care dentistry

5.4 Service provision

5.5 Attitudinal dimension

5.6 Path analysis to predict willingness to treat

5.0 Results

5.1 The sample

A total of 537 questionnaires were administered to the dentists working in primary dental care in the former NHS Board known as the Eastern Health and Social Services Board, Northern Ireland (EHSSB) and in the NHS board of Highland, Scotland (NHSH). One hundred and forty-seven questionnaires were sent to dentists working in NHSH. Three hundred and ninety were sent to dentists in the EHSSB and 42 respondents were excluded from the total sample and subsequent follow-up as they had retired (5), were on maternity leave (4), sick-leave (3), or had left the country or area (30). A second mail-out was conducted 2 months later.

Three hundred questionnaires were returned in total; 96 were from NHSH and 204 from the EHSSB. This gave an overall valid response rate of 61% (300/495). The valid response rate from NHSH was 73% and from EHSSB was 56%.

A drop-out analysis was conducted between those who had participated and those who had not. There was no significant differences in gender ($X^2[1]=0.77$:$p=0.38$) or the type of dental practice ($X^2[1]=0.11$:$p=0.74$) between those dentists who did or did not take part.

5.2 Demographic profile

Fifty-three percent (159) of the sample were male. Thirty-six percent (107) of the sample were aged between 25-35 years; 57% (171) were aged between 36-45 years

and 7% (22) were aged 46 years and over. One hundred and forty-five respondents (48%) qualified from Queen's University, Belfast; 14% (41) from University of Glasgow and 9% (27) from University of Dundee. The remaining 29% (87) of respondents qualifying from various universities such as, for example, Liverpool. The median number of years since qualification was 21-30 years, representing 120 of the participants.

Two hundred and twenty-nine (76%) of the respondents worked in the General Dental Service (GDS) and 71 (24%) worked in the Salaried Dental Service (SDS). A significantly greater proportion of dentists working in NHSH worked in the SDS (61%) compared with the EHSSB (49%) ($X^2[2]=34.87=p<0.001$). Of those 251 participants working in the GDS, 57% were predominantly NHS practices. However, significantly larger proportions of practices in EHSSB (72%) compared with NHSH (58%), were NHS practices ($X^2[1]=4.59:p=0.03$)

5.3 Dental education: training in special care dentistry

5.3.1 Undergraduate training in special care dentistry

With regard to undergraduate training, 18% (55) of the sample had benefitted from disability awareness training. The majority of the sample (77%), irrespective of area of work (EHSSB/NHSH), had no formal course in learning disability. Other items of undergraduate training in special care dentistry undertaken by the respondents are presented below in Table 1.

Table 1:Undergraduate training in special care dentistry

Item of undergraduate education	**EHSSB (n=204)** n (%)	**NHSH (n=96)** n (%)	**Total (n=300)** n (%)
1. Disability: hands-on clinical experience	22 (11)	12 (13)	34 (11)
2. Disability: knowledge	24 (12)	10 (10)	34 (11)
3. Disability: awareness training	37 (18)	18 (19)	55 (18)
4. Disability: communication skills training for patients with complex communication needs	10 (5)	6 (6)	16 (5)
5. Disability: Behavioural management for patients with complex needs	29 (14)	13 (14)	42 (14)
6. No formal course	157 (77)	73(76)	230 (77)

The five elements of undergraduate training (excluding the 'no formal course' item) were analysed together to give an undergraduate training in special care dentistry score. The score ranged from 1 to 5. Each time a respondent indicated that they had undertaken an item of training, they were awarded a score of 1. The internal reliability of the scale was assessed using the Kuder-Richardson 20 (KR20) analysis. The scale was found to have adequate reliability with KR20 = 0.65. The mean score attained for undergraduate training in special care dentistry was 1.37 (range 0-5, CI 1.27, 1.47). The median score for undergraduate training in special care dentistry was 1. Two hundred and thirty-two participants scoring 1 or less were designated as having had limited training experience as undergraduates in special care dentistry. The remaining participants scoring between 2 and 5 were designated as having had greater experience.

A univariant analysis of variance was conducted with the dependant variable being undergraduate training in special care dentistry. The between subject factors were area of work (ie NHS board), gender and age group. All main effects and two-way

interactions (gender x area of work) were inspected. The variance of 'undergraduate training in special care dentistry' was only explained significantly by the grouping variable 'age group' ($F[2, 299] = 10.92 : p<0.001$). Those participants in the youngest age group had significantly higher mean scores for undergraduate training experience compared with other groups. No other significant interactions were shown (Table 2).

Table 2: Comparison of undergraduate training experience in special care dentistry by age group

Age group	Mean* (95% CI)	F (df)	p
23-35 years	1.68 (1.53, 1.83)[2]	0.92 (2,229)	<0.001
36-45 years	1.19 (1.07, 1.32)[1]		
46-65 years	1.18 (0.84, 1.53)[1]		

The suffixes show the significant differences in mean score between age groups

*Only significant results shown: complete table of results see Appendix 10.3.

5.3.2 Postgraduate training in special care dentistry

Thirty participants (10%) were on a GDC specialist list; 7 (2%) of whom were specialist paediatric dentists, 8 (3%) were specialist orthodontists and 15 (5%) were registered on the restorative or oral surgery specialist lists. The proportion of respondents who had attended postgraduate courses was only 22% (66). However 85% (257) of the dentists stated that they would welcome additional training in special care dentistry. Equivalent proportions of dentists working in the EHSSB (58%) and NHSH (42%) stated they would welcome additional training in special

care dentistry (X^2 [1]=2.26:p=0.13). Significantly lower proportions of dentists working in GDS (85%) compared with those working in the SDS (94%) stated they would welcome postgraduate training in special care dentistry (X^2 [1]=4.20: P=0.04). Equivalent proportions of dentists working in NHS practices (88%) and private practice (82%) stated that they would welcome postgraduate training (X^2 [1]=1.29:p=0.26).

5.3.3 Current knowledge: provision of special care dentistry

Participants were asked to respond to a series of questions about their knowledge of people with LD and oral health. These questions included the prevalence of LD and the appropriate provision of care for individuals with LD. Table 3 shows the proportion of correct responses to these knowledge questions, grouped according to area of work and service type (GDS/SDS). A total (current) knowledge score on provision of special care dentistry was devised from this series of questions. Individual values for each question were awarded as follows: 1 point awarded for a correct answer and 0 awarded for an incorrect answer. The internal reliability of the scale was assessed by Kuder-Richardson 20. The total knowledge score was found to have adequate reliability with KR20 = 0.65. The scores ranged from 0 to 9. The mean score was 6.33 (CI 6.15, 6.52). The median total knowledge score was 7. Those scoring between 1 and 6 (124), were designated as having a low knowledge score in special care dentistry provision, while those with scores of 7 or higher were deemed to have a higher knowledge score (166).

Table 3: Proportion of correct responses to knowledge questions: area of work, service and practice type.

Knowledge question item	Correct responses						
	All	Area of work n (%)		Service type n (%)		Practice type (%)	
	Total n (%)	NHSH	EHSSB	GDS	SDS	NHS	Private
1. It is estimated that in the UK over 1 million people have a LD ***(Correct answer: True)***	273 (98)	87 (94)	186(91)	205 (91)	68 (100)	152 (67)	74 (33)
2. Approximately 50% of those with LD are profoundly disabled with additional disabilities ***(Correct answer: False)***	177(62)	56 (62)	121 (61)	137 (62)	40 (60)	98 (66)	50 (34)
3. More males than females are affected by LD ***(Correct answer: True)***	161 (53)	54 (62)	107 (55)	123 (57)	26 (40)	94 (69)	42 (31)
4. In individuals with LD, the poorest periodontal health is found in the 16-19 age group ***(Correct answer: True)***	114 (41)	31 (36)	83 (43)	90 (42)	24 (36)	71 (72)	28 (28)
5. Deinstitutionalisation has increased contact with dental services for those with LD ***(Correct answer: False)***	122 (43)	50 (56)	72 (37)	73 (34)	49 (74)	63 (72)	25 (28)
6. General anaesthesia is the treatment of choice for people with LD ***(Correct answer: False)***	267 (93)	88 (97)	179 (91)	199 (91)	68 (99)	145 (66)	75 (34)
7. Dentists can refuse to accept patients with LD for treatment on the basis that they may cause upset to other patients ***(Correct answer: False)***	272 (96)	85 (96)	187 (96)	211 (97)	61 (92)	154 (68)	74 (33)
8. All dental practices must complete an audit of access to inform of any physical alterations required for compliance with the DDA (DES 1995)# ***(Correct answer: True)***	240 (85)	76 (86)	164 (85)	182 (84)	58 (91)	133 (66)	68 (34)
9. Treatment and care for adults with LD unable to give informed consent, should be discussed with family, carers or advocates ***(Correct answer: True)***	274 (96)	87 (96)	187 (96)	208 (96)	66 (97)	155 (68)	74 (32)

A univariant analysis of variance was conducted, with total knowledge score as the dependent variable. As previously, the between subject factors were gender, area of work and age-group. All main effects and two-way interactions were inspected. The interaction of 'gender by area of work' significantly explained differences in current knowledge scores. Female dentists working in EHSSB had significantly higher mean total knowledge scores compared with male dentists working in EHSSB and compared with both male and female dentists working in NHSH (F[1,299]=7.58:p= 0.006) (Table 4). No other significant interactions were detected.

Table 4: Comparison of total knowledge score: provision of special care dentistry by gender and area of work

Interaction		**Mean* (95% CI)**	**F (df)**	**p**
Gender x Area of Work				
Male	NHSH	6.54 (6.07, 7.02) [1]	7.58 (1, 299)	0.006
	EHSSB	5.61 (5.12, 6.09) [1]		
Female	NHSH	5.93 (5.25, 6.59) [1]		
	EHSSB	7.01(5.93, 8.08) [2]		

The suffixes show the significant differences in mean score between gender and area of work

*Only significant results shown: complete table of results see Appendix 10.3

5.4 Service Provision

During the previous month, 61 % (184) of primary care dentists in EHSSB and NHSH said that they had treated adolescents with LD in their practices. Sixty-eight percent of the participants (205) stated that they had treated between one and five adolescents with LD in the past month. Of the remaining participants, 20% (60) stated that they had not treated any adolescents with LD, with only 12% (37) having treated 6 or more of this patient group.

Variations were noted to exist between the numbers of adolescents with LD treated per month and the type of dental service (GDS/SDS) that the respondent worked within, the area of work (EHSSB/NHSH) and their age and gender. For those dentists working within the GDS, number of adolescents with LD treated in the previous month was influenced by practice type (NHS/ private practice). With regard to area of work and age of participant, these variations were not significant. However, a significantly larger proportion of dentists working within the SDS stated that they treated more adolescents with LD in the previous month than did those dentists in the GDS ($X^2[1]=63.27:p<0.001$). Significantly larger proportions of female dentists (17.7%) compared with males dentists (7.5%), stated that they had treated more than 5 adolescents with LD in the previous month ($X^2[1]=7.17:p=0.03$). It was noteworthy that of the dentists working in private practices , none of them stated that they had treated more than 5 patients with LD in the previous month, compared with 18% of GDS dentists working in NHS practices ($X^2[1]=9.22:p=0.01$). No other significant differences were demonstrated (Table 5).

Table 5: Influence of area of work, type of service, type of GDS practice and gender and age of dentists, on numbers of adolescents with LD treated per month

Influencing factor		**Numbers of adolescents with LD treated previous month**			**X^2 [df]**	**p**
		No patients n (%)	**<5 patients n (%)**	**>6 patients n (%)**		
Area of work	NHSH (294)	20 (33)	64 (31)	12 (32)	0.73[2]	0.96
	EHSSB (96)	40 (67)	139 (69)	25 (68)		
Type of service	**GDS (229)**	**51 (22)**	**169 (74)**	**9 (4)**	**63.3[2]**	**<0.001**
	SDS (71)	**9 (12.7)**	**34 (48)**	**28 (39)**		
Type of practice	**NHS (171)**	**33 (64)**	**120 (66)**	**18 (100)**	**9.22[2]**	**0.01**
	Private (80)	**19 (37)**	**61 (34)**	**0 (0)**		
Gender	**Male (159)**	**34 (21)**	**113 (71)**	**12 (8)**	**7.17[2]**	**0.03**
	Female (141)	**26 (18)**	**90 (64)**	**25 (18)**		
Age group	Younger (106)	18 (30)	77 (38)	12 (32)	4.83[3]	0.31
	Middle (165)	34 (57)	114 (56)	23 (62)		
	Older (19)	8 (13)	12 (6)	2 (5)		

Equivalent proportions of dentists with limited (40%) compared with those with greater (32%) undergraduate experience stated that they did not treat adolescents with LD in the last month (X^2[1]=1.49:p=0.22). Similarly there was no significant difference between those dentists with low (43%) and high (35%) knowledge scores

with regard to the number of adolescents with LD (X^2[1]=2.18:p=0.14) treated in the previous month.

5.4.1 Provision of special care services

Availability of, and access to, treatment under inhalation sedation (IHS), intra-venous (IV) sedation, general anaesthetic (GA) and specialist care/services for patients with LD in EHSSB and NHSH, was examined and is summarised in Table 6.

Significantly greater proportions of dentists in EHSSB (55%) stated that they provide IHS compared with those dentists in the NHSH area (19%) (X^2[1]=33.65:p<0.001). Significantly larger proportions of dentists in the NHSH compared with EHSSB stated that the distances that patients with LD had to travel longer distances to access IV sedation (X^2[3]=59.79:p<0.001), general anaesthetic (X^2[3]=78.33:p<0.001) and specialist facilities (X^2[3]=35.03:p<0.001 compared with those dentists working in the EHSSB (Table 6).

Table 6: Availability of, and access to, sedation and specialist services for patients with LD by area of work

Service Provision Item		EHSSB n (%)	NHSH n (%)	X^2 [df]	P
Do you provide inhalation sedation (IHS)?		**113 (55)**	**18 (19)**	**33.65 [1]**	**<0.001**
Do you have access to a dental general anaesthetic service (GA)?		185 (92)	90 (98)	1.39 [1]	0.24
Do you have access to a specialist LD service?		135 (66)	68 (73)	1.30 [1]	0.26
How far do patients with LD have to travel for IV sedation?	**0-5 miles**	**77 (61)**	**14 (20)**	**59.79 [3]**	**<0.001**
	6-20 miles	**38 (30)**	**16 (23)**		
	20-40 miles	**8 (6)**	**15 (21)**		
	>40 miles	**4 (3.1)**	**26 (37)**		
How far do patients with LD have to travel for a dental GA service?	**0-5 miles**	**112 (61)**	**27 (30)**	**73.88 [3]**	**<0.001**
	6-20 miles	**59 (32)**	**20 (22)**		
	20-40 miles	**11 (6)**	**13 (14)**		
	>40 miles	**2 (1)**	**31 (34)**		
How far do patients with LD travel for a specialist LD service?	**0-5 miles**	**89 (65)**	**25 (37)**	**35.03 [3]**	**<0.001**
	6-20 miles	**40 (29)**	**19 (28)**		
	20-40 miles	**7 (5)**	**9 (13)**		
	>40 miles	**1 (1)**	**14 (21)**		

Further aspects of efficient and accessible service provision within dental surgeries in each area were examined These consisted of the inclusion of specific appointment schedules when treating patients with LD, accessibility of the surgery for wheelchair users, the provision of information regarding arrangements for out

of hours or emergency care for patients with LD and whether a hygienist was included in the dental team.

Significantly larger proportions of dentists in NHSH had wheelchair access (X^2[1]=18.30:p<0.001) and had availability of the services of a hygienist in their surgeries , compared with dentists in EHSSB. (X^2[1]=12.37:p<0.001).

Significantly greater proportions of dentists working in the SDS had an appointment schedule when treating patients with LD (X^2[1]=38.61:p<0.001) and wheelchair accessibility (X^2[1]= 19.46:p<0.001), compared with dentists working within the GDS. Although, significantly higher numbers of GDS dentists reported that they provided information on emergency care (X^2[1]=10.03:p<0.001)and had availability of a hygienist in the surgery (X^2[1]=7.61:p=0.001), compared with dentists in the SDS. For those dentists within the GDS working in NHS practices, significantly larger proportions reported use of an appointment schedule, wheelchair access, and availability of emergency information and services of a hygienist, than did dentists working in private practice. Table 7 summarises these findings.

Table 7: Access to dental services for adolescents: comparisons by area of work; service type and practice type

Dental surgery service	Area of work				Service type				Practice type			
	EHSSB n (%)	NHSH n (%)	X^2	p	GDS n(%)	SDS n(%)	X^2	p	NHS n(%)	Private n(%)	X^2	p
Do you have an appointment schedule when treating patients with LD?	29 (14)	14 (15)	0.25	0.88	**17 (40)**	**26 (61)**	**38.61**	**<0.001**	18 (72)	7 (28)	0.25	0.62
Is your surgery accessible for wheelchairs?	**119 (59)**	**79 (84)**	**18.30**	**<0.001**	**136 (60)**	**62 (89)**	**19.46**	**<0.001**	**96 (63)**	**57 (37)**	**4.34**	**0.04**
Do you provide information on emergency care?	143 (67)	70 (75)	0.74	0.39	**153 (72)**	**60 (28)**	**10.03**	**<0.001**	121 (71)	49 (29)	2.92	0.09
Do you have a hygienist in your practice?	**96 (47)**	**65 (69)**	**12.37**	**<0.001**	**113 (70)**	**48 (30)**	**7.61**	**0.01**	**67 (52)**	**63 (49)**	**32.83**	**<0.001**

5.4.2 Effect of training and knowledge on provision of special care dental services.

The relationship between previous dental education of dentists and the provision of services for the treatment of individuals with LD was investigated. The previously described 'undergraduate training in special care dentistry score' and the 'total current knowledge score', were used to analyse the effect of dentists' undergraduate training (limited vs. greater experience) and knowledge (lower vs. higher knowledge) on the provision of IHS , appointment scheduling, wheelchair access, emergency care information and access to the services of a hygienists ,within their dental surgeries. No significant findings were found (Table 8).

Table 8: Access to dental services for adolescents with LD : comparisons by undergraduate training and knowledge of LD

Dental surgery service	Undergraduate training				Knowledge of LD			
	Limited n (%)	Greater n (%)	X^2	P	Lower n(%)	Higher n(%)	X^2	p
Do you provide IV for patients with LD?	39 (17)	13 (19)	1.01	0.58	26 (50)	26 (50)	0.88	0.64
Do you provide inhalation sedation for patients with LD?	98 (43)	33 (49)	0.70	0.40	55 (42)	76 (58)	0.43	0.51
Do you have an appointment schedule when treating patients with LD?	37 (16)	6 (9)	2.35	0.13	18 (14)	25 (15)	0.07	0.79
Is your surgery accessible for wheelchairs?	152 (66)	46 (69)	0.12	0.73	90 (46)	108 (55)	0.35	0.56
Do you provide information on emergency care?	166 (73)	47 (69)	0.35	0.55	92 (70)	121 (73)	0.34	0.55
Do you have a hygienist in your practice?	121 (53)	40 (59)	0.78	0.38	67 (51)	94 (57)	0.89	0.35

5.4.3 Intention to provide dental treatment for adolescents with increasing severity of LD

Figure 3 shows the mean scores for the intention to provide dental care for adolescents with mild, moderate and severe LD.

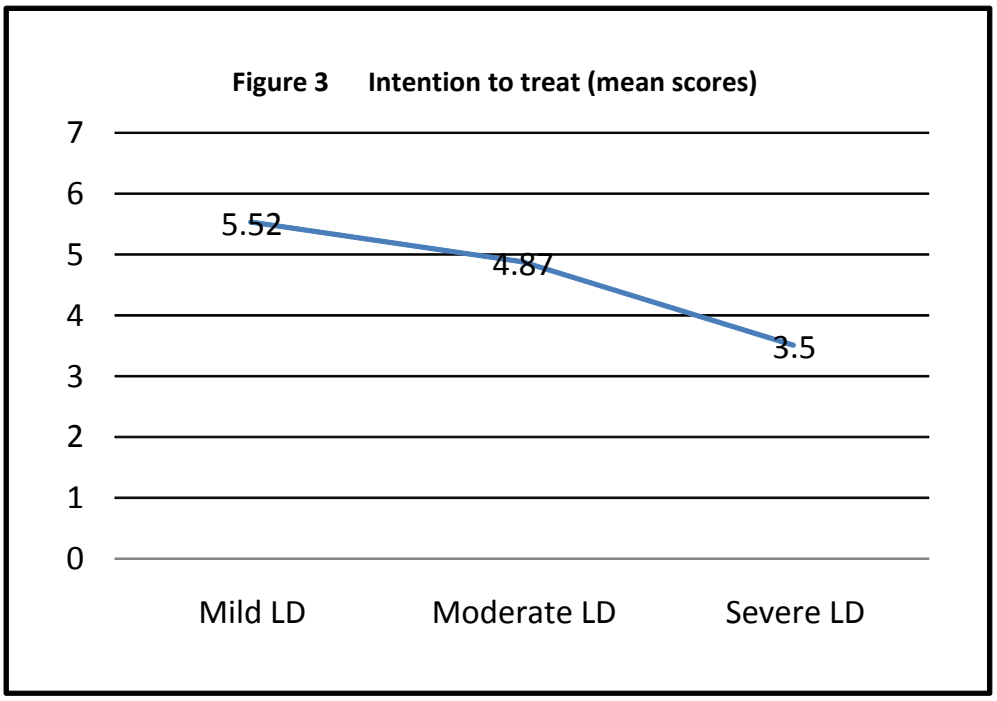


Table 9 shows that there were significant differences between the mean scores for the intentions to treat adolescents with varying degrees of severity of learning disability.

Table 9: Intention to treat: comparison by severity of LD

Intention to treat adolescents with LD Mean (SD)		**t**	**P**
Mild LD 5.52 (1.69)	Moderate LD 4.83 (1.83)	8.82	<0.001
Mild LD 5.52 (1.69)	Severe LD 2.73 (1.98)	22.87	<0.001
Moderate LD 4.83 (1.83)	Severe LD 2.73 (1.98)	21.83	<0.001

5.4.4 Intention to provide dental treatment for adolescents with increasing severity of LD: area of work; service type; undergraduate training and knowledge of LD

- Area of work: EHSSB or NHSH

Dentists working in the NHSH had significantly higher mean scores (3.14) for the intention to treat adolescents with severe LD compared to those who worked in EHSSB (2.53) (t=2.31:p=0.02). No other significant differences were shown for intention to treat adolescents with mild or moderate LD by area of work.

- Service type: GDS or SDS

Dentists working in the SDS had significantly higher mean scores for the intention to treat adolescents with mild, moderate or severe LD compared to those who worked in GDS (Table 10).

Table 10: Intention to treat adolescents with LD of varying severity: SDS and GDS service type

Intention to treat adolescents with LD Mean (SD)				
Degree of LD	GDS Mean (SD)	SDS Mean (SD)	**t**	**P**
Mild LD	5.32 (1.67)	6.20 (1.56)	3.92	<0.001
Moderate LD	4.50 (1.76)	6.03 (1.53)	7.01	<0.001
Severe LD	2.19 (1.52)	4.49 (2.28)	7.77	<0.001

- Undergraduate training experience: limited and greater experience

There were no significant differences between mean scores for the intention to treat adolescents with mild, moderate or severe LD by undergraduate training experience.

- Knowledge of LD: lower and greater knowledge

Dentists with greater knowledge of LD had significantly higher mean scores for the intention to treat adolescents with mild, moderate or severe LD compared to those with lower knowledge (Table 11).

Table 11: Intention to treat adolescents with LD of varying severity: Knowledge levels

Intention to treat adolescents with LD Mean (SD)				
Degree of LD	Lower knowledge Mean (SD)	Higher knowledge Mean (SD)	**t**	**P**
Mild LD	5.20 (1.83)	5.77 (1.53)	2.84	0.005
Moderate LD	4.54 (1.89)	5.12 (1.72)	2.71	0.007
Severe LD	2.37 (1.89)	3.01 (1.73)	2.80	0.005

5.4.5 Willingness to treat scale (W2TS)

A **W**illingness **to** **T**reat **S**cale (W2TS) was commutated and was composed of:

1. The three intention variables to treat adolescent patients with mild, moderate and severe LD;
2. Confidence to treat adolescents with LD;
3. How much do you want to treat adolescents with LD;

4. How stressful do you find it to treat individuals with LD.

Table 12 shows the correlation analysis between the 6 items composing the W2TS. The items were highly positively and significantly associated with one another suggesting that they comprised a scale.

Table 12: Correlation matrix of 6 items of the W2TS

		Do you intend to treat adolescents with MLD?	Do you intend to treat adolescents with MoLD?	Do you intend to treat adolescents with SLD?	How confident are you that you can treat patients LD?	How much do you want to treat adolescents with LD?	How stressful is it for you to treat people with LD?
Do you intend to treat adolescents with MLD?	Pearson Correlation	1	.722**	.399**	.369**	.461**	.263**
	Sig. (2-tailed)		.000	.000	.000	.000	.000
	N	286	283	281	284	285	285
Do you intend to treat adolescents with MoLD?	Pearson Correlation	.722**	1	.623**	.507**	.627**	.316**
	Sig. (2-tailed)	.000		.000	.000	.000	.000
	N	283	293	289	285	286	286
Do you intend to treat adolescents with SLD?	Pearson Correlation	.399**	.623**	1	.460**	.613**	.368**
	Sig. (2-tailed)	.000	.000		.000	.000	.000
	N	281	289	291	283	284	284
How confident are you that you can treat patients LD?	Pearson Correlation	.369**	.507**	.460**	1	.607**	.495**
	Sig. (2-tailed)	.000	.000	.000		.000	.000
	N	284	285	283	288	288	288
How much do you want to treat adolescents with LD?	Pearson Correlation	.461**	.627**	.613**	.607**	1	.515**
	Sig. (2-tailed)	.000	.000	.000	.000		.000
	N	285	286	284	288	289	289
How stressful is it for you to treat people with LD?	Pearson Correlation	.263**	.316**	.368**	.495**	.515**	1
	Sig. (2-tailed)	.000	.000	.000	.000	.000	
	N	285	286	284	288	289	289

**. Correlation is significant at the 0.01 level (2-tailed).

A principle components factor analysis was conducted. Table 13 shows the Cronbach's alpha, factor loading and means and 95% confidence intervals for the W2TS. The factor was called 'willingness to treat' with an eigenvalue of 3.48, explaining 58.08% of the variance. The W2TS had a range of 0-42, with a higher score indicating a greater willingness to provide treatment for patients with LD than a lower score.

Table 13: Willingness to treat scale (means, 95% confidence intervals and reliabilities) and items (means, 95% confidence intervals and factor loadings)

Willingness to treat (W2T) item	**Cronbach α**	**Factor Loading**	**Mean (95% CI)**
1. Intention to treat adolescents with mild LD	0.85	0.70	5.51 (5.31, 5.71)
2. Intention to treat adolescents with moderate LD		0.85	4.84 (4.63, 5.06)
3. Intention to treat adolescents with severe LD		0.78	2.75 (2.51, 2.98)
4. Confidence treat adolescents with LD		0.75	3.70 (3.53, 3.86)
5. How much do you want to treat adolescents with LD		0.85	3.57 (3.38, 3.77)
6. How stressful to treat adolescents with LD		0.62	3.21 (3.03, 3.39)
Total willingness to treat item score			**23.58 (22.67, 24.50)**

This scale was used to conduct a univariant analysis of variance, with willingness to treat as the dependant variable. Again, the between subject factors were gender, area of work and three-category age-groups. Results from this analysis show the variance of willingness to treat was explained significantly by the effects of gender ($F[1,299] = 7.49$:$p=0.01$) and three-category age groups ($F[2,299] = 3.33$:$p=0.037$) The two-way interaction of area of work x age-group demonstrated significantly

higher willingness to treat scores for dentists in the younger age category in NHSH (F[1, 299] = 4.22 : p = 0.016). Significant results are summarised in Table 14.

Table 14: Comparison of willingness to treat adolescents with LD: provision of special care dentistry by gender, area of work and age group.

Main effects		**Mean* (95% CI)**	**F (df)**	**p**
Age group	23-35 years	26.50 (24.66-28.35)	3.33[2,299]	**0.04**
	36-45 years	23.62 (22.35-24.89)		
	46-65 years	25.68 (20.94-30.42)		
Gender	Male	22.84 (21.08-24.59)	7.49 [1,299]	**0.01**
	Female	27.70 (28.68-30.72)		

Two-way interaction Area of work x age group		**Mean* (95% CI)**	**F (df)**	**p**
EHSSB	23-35 yrs	23.28 (21.61-24.95)	4.22 [2,299]	**0.02**
	36-45 yrs	22.09 (20.65-23.54)		
	46-65 yrs	29.75 (21.58-37.92)		
NHSH	23-35 yrs	29.73 (26.44-33.01)		
	36-45 yrs	25.14 (23.05-27.23)		
	46-65 yrs	21.62 (16.81-26.43)		

*significant results only displayed

5.5 Attitudinal dimension

The two attitude scales, (Bedi et al, 2000, Coyle et al 2004[1]), described previously, were examined separately to determine if the responses given were influenced by area of work, age-grouping or gender of the participants, and the presence, if any, of underlying themes that would account for such variations.

5.5.1 Attitudinal dimension: The Bedi (2000) scale

The Bedi scale consisted of 20 items, which examined dental personnel attitudes towards patients with LD specifically in the dental setting. It has previously been shown to have good internal consistency and reliability (Bedi et al, 2000).

When the mean scores for responses to individual items on the questionnaire were examined several significant differences were noted between the area of work, genders and age groups. These are summarised as follows:

- Dentists working in the EHSSB compared with those working in the NHSH had significantly higher mean scores for Attitudes 4, 11 and 14 (Table 15).
- Male compared with female dentists had significantly higher mean scores for Attitudes 4, 5, 8, 20, 13 and 17. Female compared with male dentists

[1] The scale developed by Coyle et al (2004) was found to have poor internal consistency with this sample of qualified dentists. In view of this the scale developed by Bedi et al (2000) was used in the subsequent analysis of the data. The principle component analysis table for the questionnaire developed by Coyle et al (2004) is included in Appendix 10.4 for completeness.

has significantly higher mean scores for Attitudes 7, 11, 12 and 16 (Table 16).

- Younger dentists compared with the older age groups had significantly higher mean scores for Attitudes 7 and 16. Oldest dentists compared with other age groups had significantly higher mean scores for Attitudes 8 and 17 (Table 17).

Table 15: Comparison of mean scores for individual attitudes by area of work

Attitudes	EHSSB (n=204) Mean (SD)	NHSH (n=96) Mean(SD)	t	p
1. People with LD can be expected to reach the same standard of oral hygiene as other people	3.10 (1.13)	3.20 (1.07)	-0.691	0.49
2. People with a LD are able to make decisions about their own health care	3.48 (0.92)	3.64 (0.88)	-1.41	0.16
3. It is impossible to keep the teeth dry when working on people with a LD	2.29 (0.86)	2.04 (0.83)	2.26	0.25
4. Patients with a LD are too disruptive in the dentists' chair to allow proper treatment	**2.29* (0.88)**	**2.07 (0.79)**	**2.18**	**0.03**
5. Oral hygiene instruction for people with a LD has little or no effect	2.17 (0.80)	2.14 (0.91)	0.23	0.82
6. Aesthetic dental treatment is as important for people with a LD as it is for other people	3.71 (1.02)	3.87 (0.96)	-1.30	0.20
7. People with a LD are able to successfully adjust to life outside an institutional setting.	3.57 (0.83)	3.76 (0.81)	-1.89	0.06
8. Dentists should reserve the right not to treat people with a LD	2.65 (1.19)	2.80 (1.28)	-0.94	0.35
9. Patients with a LD pose no special health risks to other patients and dental personnel	3.63 (1.09)	3.81 (1.05)	-1.34	0.18
10. Dentists should be paid a lot more for treating people with a LD than for treating other people	3.81 (1.02)	3.58 (1.04)	1.74	0.08
11. People with a LD can be trusted to keep their dental appointments as much as anyone else	**3.42 (1.00)**	**3.12 (0.98)**	**2.35**	**0.02**
12. Treating patients with a LD is highly rewarding	3.77 (0.94)	3.79 (0.88)	-0.18	0.86
13. Patients with a LD upset other patients in the waiting room	2.31 (0.82)	2.34 (0.90)	-0.29	0.78
14. Dentists should refuse to treat people with a LD unless they are accompanied by a responsible person	**3.08 (1.05)**	**2.71 (0.88)**	**3.11**	**0.00**
15. Each dental case should be assessed individually irrespective of whether the patient has a LD	4.47 (0.74)	4.61 (0.63)	-1.67	0.10
16. Laws should be enforced to prevent dentists from discriminating against people with a LD	3.42 (1.13)	3.23 (1.32)	1.14	0.26
17. There is no point in discussing a treatment plan with people with a LD, as they will not understand it	2.07 (0.81)	1.92 (0.80)	1.40	0.16
18. Treating patients with a LD causes too much stress for the dental team	2.38 (0.90)	2.19 (0.80)	1.65	0.10
19. It is better for all concerned if people with a LD attend specialist clinics rather than general dental practices	2.73 (0.99)	2.49 (1.01)	1.85	0.07
20. People with a LD should receive the same quality of care as others	4.46 (0.63)	4.56 (0.62)	-1.21	0.23

*Significant results are displayed in bold

Table 16: Comparison of mean scores for individual attitudes between male and female dentists

Attitude	Male (n=159) Mean* (SD)	Female (n=141) Mean* (SD)	t	p
1. People with LD can be expected to reach the same standard of oral hygiene as other people	3.05 (1.17)	3.23 (1.04)	-1.41	0.16
2. People with a LD are able to make decisions about their own health care	3.52 (0.91)	3.54 (0.91)	-0.11	0.91
3. It is impossible to keep the teeth dry when working on people with a LD	2.26 (0.84)	2.16 (0.88)	1.03	0.30
4. Patients with a LD are too disruptive in the dentists' chair to allow proper treatment	**2.33 (0.83)**	**2.11 (0.87)**	**2.23**	**0.03**
5. Oral hygiene instruction for people with a LD has little or no effect	**2.27 (0.86)**	**2.05 (0.80)**	**2.23**	**0.03**
6. Aesthetic dental treatment is as important for people with a LD as it is for other people	3.65 (0.94)	3.87 (1.06)	-1.91	0.06
7. People with a LD are able to successfully adjust to life outside an institutional setting.	**3.53 (0.80)**	**3.73 (0.84)**	**-2.10**	**0.04**
8. Dentists should reserve the right not to treat people with a LD	**2.89 (1.27)**	**2.49 (1.14)**	**2.78**	**0.01**
9. Patients with a LD pose no special health risks to other patients and dental personnel	3.68 (1.14)	3.68 (1.01)	-0.27	0.98
10. Dentists should be paid a lot more for treating people with a LD than for treating other people	**3.85 (1.01)**	**3.61 (1.03)**	**2.05**	**0.04**
11. People with a LD can be trusted to keep their dental appointments as much as anyone else	**3.19 (1.02)**	**3.46 (0.94)**	**-2.36**	**0.02**
12. Treating patients with a LD is highly rewarding	**3.64 (0.82)**	**3.92 (0.10)**	**-2.63**	**0.01**
13. Patients with a LD upset other patients in the waiting room	**2.44 (0.87)**	**2.18 (0.80)**	**2.70**	**0.01**
14. Dentists should refuse to treat people with a LD unless they are accompanied by a responsible person	3.07 (1.05)	2.86 (0.96)	1.78	0.08
15. Each dental case should be assessed individually irrespective of whether the patient has a LD	4.50 (0.70)	4.53 (0.72)	-0.34	0.73
16. Laws should be enforced to prevent dentists from discriminating against people with a LD	**3.19 (1.27)**	**3.55 (1.09)**	**-2.60**	**0.01**
17. There is no point in discussing a treatment plan with people with a LD, as they will not understand it	**2.12 (0.84)**	**1.91 (0.76)**	**2.19**	**0.03**
18. Treating patients with a LD causes too much stress for the dental team	2.42 (0.92)	2.21 (0.86)	1.92	0.06
19. It is better for all concerned if people with a LD attend specialist clinics rather than general dental practices	2.71 (1.00)	2.59 (1.00)	1.09	0.28
20. People with a LD should receive the same quality of care as others	4.46 (0.63)	4.52 (0.63)	-0.83	0.41

*****Significant results are displayed in bold

Table 17: Comparison of mean scores for individual attitudes by age group

Attitude	23-35 yrs Mean (95% CI)	36-45 yrs Mean (95% CI)	46-65 yrs Mean (95% CI)	F (df)	p
1. People with LD can be expected to reach the same standard of oral hygiene as other people	3.18 (2.97-3.39)	3.07 (2.90-3.25)	3.42 (2.99-3.86)	0.98 (2, 288)	0.38
2. People with a LD are able to make decisions about their own health care	3.64 (3.48-3.81)	3.45 (3.30-3.60)	3.58 (3.18-3.98)	1.43 (2, 288)	0.24
3. It is impossible to keep the teeth dry when working on people with a LD	2.13 (1.97-2.30)	2.25 (2.11-2.38)	2.32 (1.92-2.71)	0.73 (2, 288)	0.48
4. Patients with a LD are too disruptive in the dentists' chair to allow proper treatment	2.15 (1.98-2.32)	2.26 (2.14-2.39)	2.26 (1.81-2.71)	0.58 (2, 288)	0.56
5. Oral hygiene instruction for people with a LD has little or no effect	2.11 (1.94-2.29)	2.19 (2.07-2.31)	2.21 (1.83-2.59)	0.29 (2, 288)	0.75
6. Aesthetic dental treatment is as important for people with a LD as it is for other people	3.69 (3.50-3.88)	3.79 (3.63-3.95)	3.84 (3.44-4.24)	0.39 (2, 288)	0.68
7. People with a LD are able to successfully adjust to life outside an institutional setting.	**3.82 (3.69-3.96)**	**3.53 (3.40-3.67)**	**3.37 (2.94-3.80)**	**5.04 (2, 288)**	**0.01**
8. Dentists should reserve the right not to treat people with a LD	**2.49 (2.26-2.72)**	**2.78 (2.59-2.97)**	**3.11 (2.51-3.70)**	**3.01 (2, 288)**	**0.05**
9. Patients with a LD pose no special health risks to other patients and dental personnel	3.62 (3.40-3.84)	3.72 (3.56-3.88)	3.68 (3.17-4.19)	0.26 (2, 288)	0.77
10. Dentists should be paid a lot more for treating people with a LD than for treating other people	3.60 (3.40-3.80)	3.84 (3.69-4.00)	3.53 (3.01-4.04)	2.18 (2, 288)	0.12
11. People with a LD can be trusted to keep their dental appointments as much as anyone else	3.42 (3.23-3.61)	3.25 (3.10-3.40)	3.42 (2.99-3.86)	1.13 (2, 288)	0.33
12. Treating patients with a LD is highly rewarding	3.68 (3.50-3.86)	3.86 (3.72-4.00)	3.58 (3.21-3.95)	1.71 (2, 288)	0.18
13. Patients with a LD upset other patients in the waiting room	2.17 (2.10-2.33)	2.38 (2.25-2.51)	2.61 (2.19-3.03)	3.13 (2, 288)	0.45
14. Dentists should refuse to treat people with a LD unless they are accompanied by a responsible person	2.87 (2.68-3.06)	3.06 (2.90-3.22)	2.68 (2.23-3.14)	1.97 (2, 288)	0.14
15. Each dental case should be assessed individually irrespective of whether the patient has a LD	4.55 (4.42-4.68)	4.51 (4.40-4.62)	4.37 (4.00-4.74)	0.52 (2, 288)	0.60
16. Laws should be enforced to prevent dentists from discriminating against people with a LD	**3.63 (3.41-3.84)**	**3.25 (3.07-3.44)**	**2.7 (2.12-3.46)9**	**5.62 (2, 288)**	**<0.001**
17. There is no point in discussing a treatment plan with people with a LD, as they will not understand it	**1.82 (1.69-1.96)**	**2.13 (2.00-2.26)**	**2.16 (1.72-2.59)**	**5.29 (2, 288)**	**0.01**
18. Treating patients with a LD causes too much stress for the dental team	2.25 (2.10-2.42)	2.34 (2.21-2.47)	2.56 (2.10-3.10)	1.02 (2, 288)	0.36
19. It is better for all concerned if people with a LD attend specialist clinics rather than general dental practices	2.69 (2.51-2.87)	2.62 (2.46-2.78)	2.74 (2.18-3.29)	0.23 (2, 288)	0.79
20. People with a LD should receive the same quality of care as others	4.57 (4.46-4.67)	4.45 (4.35-4.56)	4.37 (4.00-4.74)	1.39 (2, 288)	0.25

*****Significant results are displayed in bold

All of the scores for the 20 attitudinal items on the Bedi questionnaire, were then subjected to a principle components analysis. Two components were identified which explained 35.52% of the total variance. Scale 1 was composed of items 3, 4, 5, 8, 10, 13, 14, 17, 18, 19, to become conceptualised as the 'clinical factor'. It explained 26.26% of the variance and had an eigenvalue of 5.25. Scale 2 was composed of items 1, 2, 6, 7, 9, 11, 12, 15, 16, 20, and reflected the 'social factor' of participants' attitudes. It explained 9.25 % of the variance, with an eigenvalue of 1.85. Internal consistency and reliability of the two scales was found to be high, with the clinical factor scale having a Cronabach α value of 0.81, and the social factor scale having a Cronbach α value of 0.72 (Table 18).

Table 18: Attitudinal Scale (means, 95%CI and reliabilities) and items (means, 95%CI and factor loadings).

Attitudinal items	Cronbach Alpha	Factor loading	Mean (95%CI)
Clinical Factor Scale	**0.81**		**25.38 (24.74,26.03)**
3.It is impossible to keep the teeth dry when working on people with a LD		0.60	2.20(2.10, 2.30)
4.Patients with a LD are too disruptive in the dentists' chair to allow proper treatment		0.66	2.23 (2.13, 2.33)
5.Oral hygiene instruction for people with a LD has little or no effect		0.53	2.18 (2.08, 2.28)
8.Dentists should reserve the right not to treat people with a LD		0.54	2.69 (2.55, 2.84)
10.Dentists should be paid a lot more for treating people with a LD than for treating other people		0.54	3.75 (3.62, 3.87)
13.Patients with a LD upset other patients in the waiting room		0.35	2.31 (2.21, 2.41)
14.Dentists should refuse to treat people with a LD unless they are accompanied by a responsible person		0.57	2.94 (2.82, 3.05)
17.There is no point in discussing a treatment plan with people with a LD, as they will not understand it		0.67	2.02 (1.93, 2.12)
18.Treating patients with LD causes too much stress for the dental team		076	2.34 (2.23, 2.45)
19.It is better for all concerned if people with LD attend specialist clinics rather than general dental practices		0.65	2.67 (2.55, 2.79)
Social Factor Scale	**0.72**		**37.09 36.53, 37.66)**
1.People with LD can be expected to reach the same standard of OHI as other people		0.62	3.11 (2.98, 3.25)
2.People with LD are able to make decisions about their own health care		0.64	3.52(3.41, 3.62)
6.Aesthetic dental treatment is as important for people with LD as it is for other people		0.62	3.75 (3.63, 3.87)
7.People with LD are able to successful adjust to life outside an institutional setting		0.68	3.61 (3.52, 3.71)
9.Patients with LD pose no special health risks to other patients and dental personnel		0.27	3.67 (3.54, 3.79)
11.Patients with LD can be trusted to keep their dental appointments as much as anyone else		0.47	3.31 (3.19, 3.42)
12.Treating patients with LD is highly rewarding		0.42	3.75 (3.64, 3.86)
15.Each dental care should be assessed individually irrespective of whether the patient has an LD		0.53	4.51 (4.42, 4.59
16.Laws should be enforced to prevent dentists from discriminating against people with an LD		0.30	3.35 (3.21, 3.49)
20.People with LD should receive the same quality of care as others		0.59	4.48 (4.41, 4.55)

5.5.1.1 Clinical factor scale

The mean total clinical factor score for all of the respondents was 25.38, with a range of 24.74 - 26.03. The mean scores were analysed by area of work, gender and age grouping. Male compared with female dentists had significantly higher mean scores for the clinical factor and older dentists had significantly higher mean scores than other age groups (Table 19).

Table 19: Influence of area of work, gender and age group on total mean clinical factor scores.

		Mean (SD)	**t**	**p**
Area of work	EHSSB	25.7 (5.57)	1.71	0.09
	NHSH	24.5 (5.80)		
Gender	**Male**	**26.5 (5.41)**	**3.69**	**<0.001**
	Female	**24.1 (5.70)**		
		Mean (95% CI)	**F(df)**	**p**
Age group	**23-35 years**	**24.3 (23.20-25.42)**	3.67[2, 299]	**0.03**
	36-45 years	**25.8 (25.0-26.70)**		
	46-65 years	**26.09 (24.53-29.93)**		

A univariant analysis of variance was conducted, with total clinical factor score as the dependent variable. The between subject factors were area of work, gender and age-group. All main effects and two-way interactions were inspected. It was found that the grouping variable gender explained the variance in the clinical factor scores. Female dentists (23.69 [95% CI: 22.13, 25.25]) compared with male

dentists (26.25 [95%CI: 25.19, 27.31]) had significantly lower mean scores for total clinical factor (F[1,288]=6.40:p=0.01). A complete table of results is presented in Appendix 10.3.

5.5.1.2 Bedi Scale: Social factors

The mean total social factor score for all of the respondents was 37.10, with a range of possible scores of 18-50.

The mean total social factor scores were analysed by area of work, gender and age grouping. It was noted that both area of work and age group did not influence the mean social factor scores. However, gender was found to have an effect, with female dentists having significantly higher mean social factor scores than male dentists (t [1,298]=-3.03:p=0.003). (Table 20).

Table 20: Influence of area of work, gender and age group on total mean social factor scores.

		Mean (SD)	**t**	**p**
Area of work	EHSSB (294)	36.9 (5.11)	-0.82	0.42
	NHSH (96)	37.4 (4.71)		
Gender	Male (159)	36.3 (4.84)	-3.03	**0.003**
	Female (141)	38.0 (5.01)		
		Mean (95% CI)	**F(df)**	**p**
Age group	23-35 years (107)	37.8 (36.80-38.73)	1.53[2,299]	0.21
	36-45 years (171)	36.8 (36.03-37.53)		
	46-65 years (22)	36.3 (34.25-38.36)		

A univariant analysis of variance was conducted, with total social factor score as the dependent variable. The between subject factors were area of work, gender and age-group. All main effects and two-way interactions were inspected. The interaction of area of work, gender and age group, did not explain the variance in the clinical factor scores (see Appendix 10.3).

5.6 Path analysis to predict willingness to treat

In order to predict the Willingness to Treat belief held by the dentists, in the samples from both Northern Ireland and Scotland (i.e. total sample pooled together), four main variables were employed. These were labelled as the independent variables including: training received at undergraduate Level, knowledge, social and clinical factors. The variables however were ordered into

two stages, proximal and distal. The model prepared was constructed from knowledge of the field and broad theoretical principles that training and knowledge would inform attitudes and beliefs of participants which in turn would influence willingness to treat patients with LD.

The assigned proximal variables included the social and clinical factors. That is these two variables were considered to be the closest associated with the dependent variable of Willingness to Treat. The two assigned distal variables included the training at undergraduate level and the knowledge scale. All variables were entered as raw variables. Inspection of the distribution of the scales confirmed that all measures included in the model were normally distributed. The exception to this consistency was the training at undergraduate level which was positively skewed. Estimates of association from this measure were treated with caution, although all other measures were normally distributed ensuring that any potential biases were not magnified.

AMOS version 17 was used to prepare a path model using the accessible 'diagrammer' for specifying the model (figure 4). All indirect and direct paths were included. Error terms were entered into the model for those variables that acted as non-independent predictors. Likewise the dependent variable required an error term. All error terms had their regression weights set to unitary to enable convergence of the estimation procedures (that is the model was identified).

Maximum likelihood estimation was employed as the most efficient method to derive model parameters. By convention the correlation between the knowledge and treatment at undergraduate level was entered. Hence the effects of each of these two distal variables will be independent of the effect of the other when interpreting their separate paths in the overall model. Initial results showed that three paths were redundant ($p > 0.05$) and these were removed for the sake of parsimony and ease of interpretation. These were the two direct effects of the knowledge and treatment at undergraduate level on Willingness to Treat. This demonstrated that the position of these two variables as 'distal' rather than 'proximal' to Willingness to Treat was consistent with the initial proposed model. The third path of knowledge to clinical factors was also dropped from the model (z = 1.48, p = 0.138).

The resulting model was run using the complete data set with no missing values (n = 277). No alerts were raised by the estimation procedure and all coefficients were within conventional limits. A maximum of 8 iterations was required to achieve convergence. The standardised model is presented in figure 5 showing all paths were statistically significant. The correlation between the two distal variables (training and knowledge) was non-significant but retained in the model for the sake of completeness and enable clear interpretation of these variables on the social and clinical factors. The overall fit of the data to the specified model was excellent as shown by the low chi square value ($\chi^2 = 4.18$, = 3, p = 0.243) and the X^2/ df ratio was

less than two (namely 1.392). The three common fit indices confirmed close correspondence of the data to the model: *CFI* = 0.994; *TLI* = 0.981; *RMSEA* = 0.038.

Table 21: Correlation matrix of variables included in path analysis

		willlingness to treat scale	social factor	clinical factor	total knowledge score	undergraduate training experience
willingness to treat scale	Pearson Correlation	1	.448**	-.544**	.169**	.154*
	Sig. (2-tailed)		.000	.000	.005	.011
social factor	Pearson Correlation	.448**	1	-.492**	.171**	.125*
	Sig. (2-tailed)	.000		.000	.004	.037
clinical factor	Pearson Correlation	-.544**	-.492**	1	-.132*	-.166**
	Sig. (2-tailed)	.000	.000		.028	.006
total knowledge score	Pearson Correlation	.169**	.171**	-.132*	1	.047
	Sig. (2-tailed)	.005	.004	.028		.431
undergraduate training experience	Pearson Correlation	.154*	.125*	-.166**	.047	1
	Sig. (2-tailed)	.011	.037	.006	.431	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

a. Listwise N=277

Figure 4 Initial Model proposed with all paths included

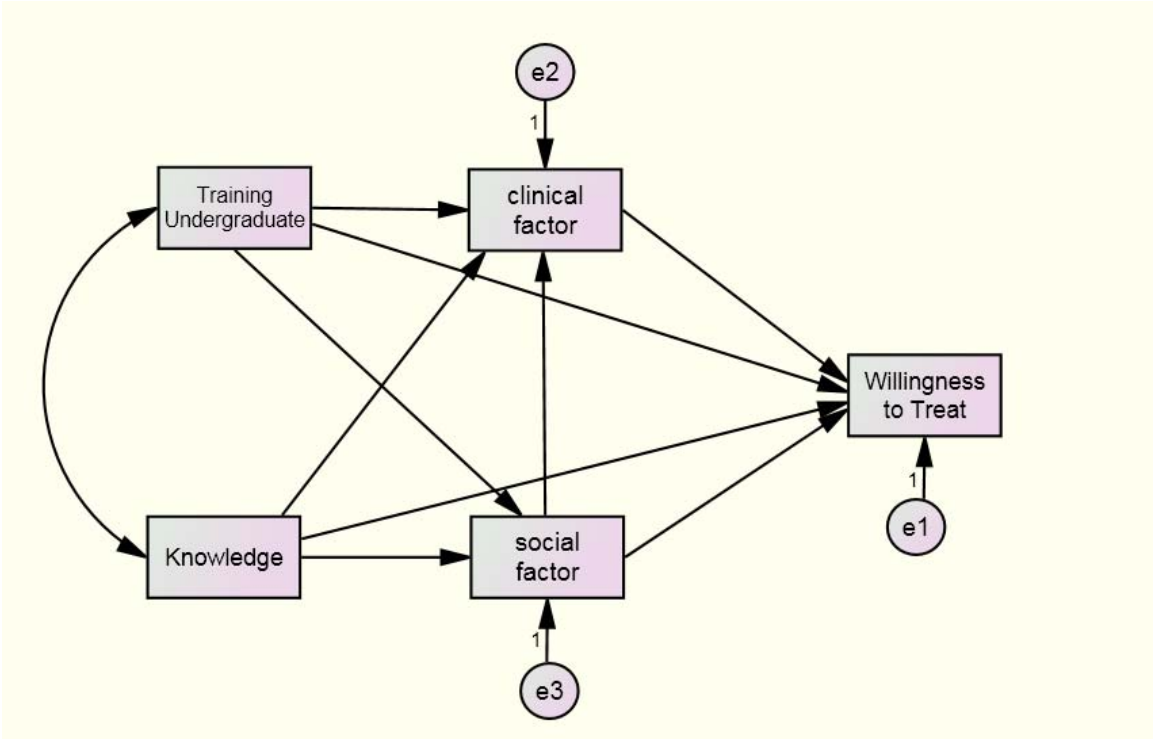
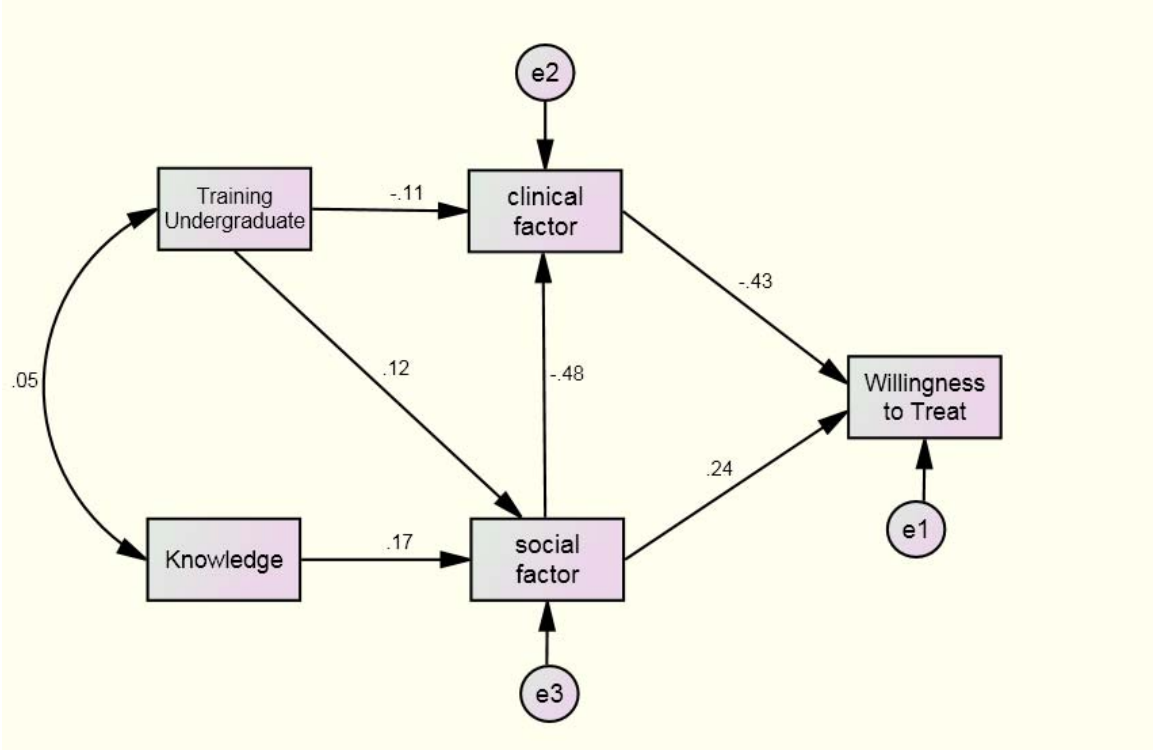


Figure 5 Results of final path analysis model for whole study sample (n = 277)



A further check was made to ascertain the similarity of the results of these associations across the two countries (Northern Ireland and Scotland). This was achieved by running a simultaneous fitting procedure on the sets of data from both countries. The paths of the models from both countries were allowed to estimated freely (see figures 6 and 7) and then a further model run which constrained the path estimates to be equal across countries. Fit statistics are displayed by country sub-sample in Table 22.

Table 22: Fit statistics and indices for country sub-samples

	χ^2	df	p	χ^2/df	CFI	TLI	RMSEA
Northern Ireland	7.57	3	.056	2.52	0.968	0.892	.090
Scotland	0.06	3	.996	0.02	1.000	1.000	.001

The Scottish sub sample (n = 89) showed virtually little discrepancy between the model specification and raw data as shown by the very low chi square value. The omnibus test to compare the constrained and unconstrained models demonstrated that the differences in associations observed between the two countries were more apparent than real as shown by a non significant association (χ^2 = 3.954, df = 6, p = 0.683) – probably due to the relatively small sample size in Scotland.

Figure 6 Results of path analysis model for NI sub-sample (n = 188)

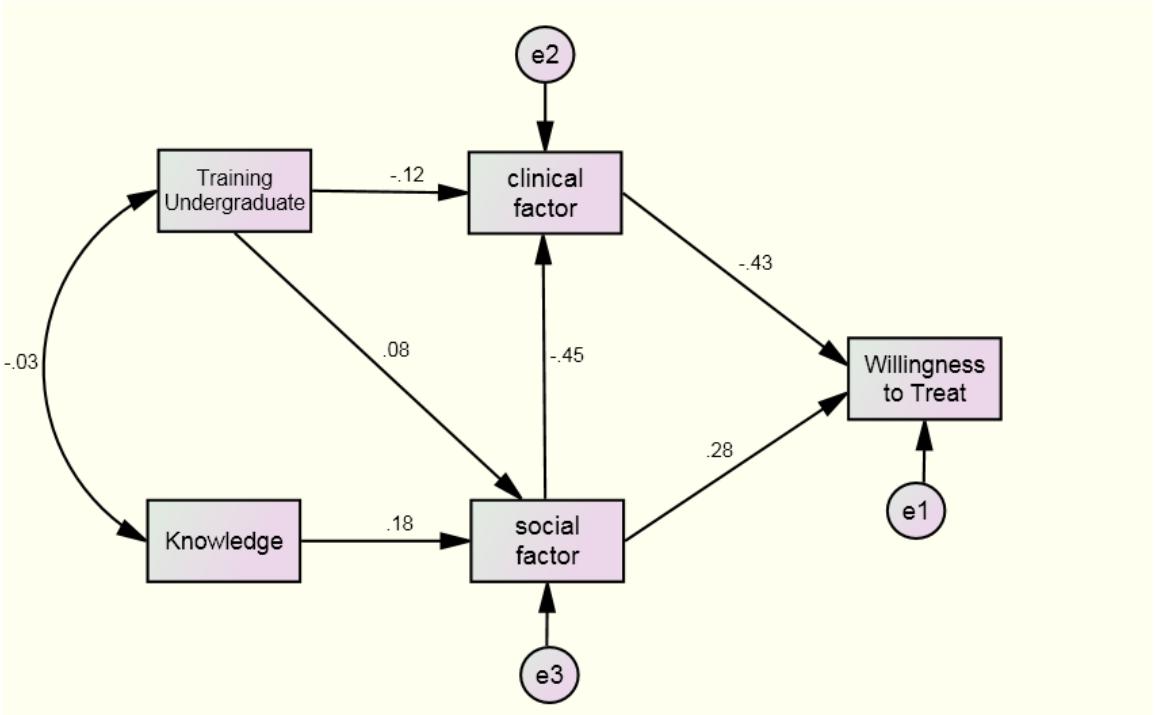
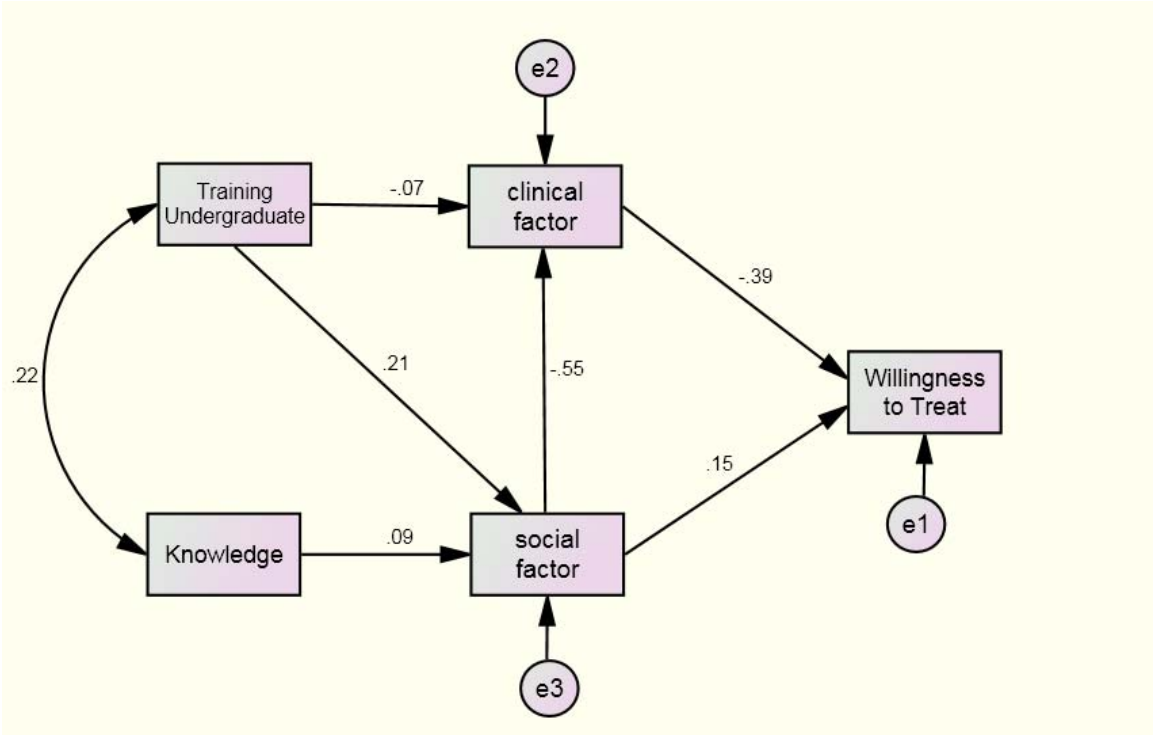


Figure 7 Results of path analysis model for Scottish sub-sample (n = 89)



6.0 Discussion

6.0 Discussion

6.1 Introduction

The aim of the study was to examine primary dental care practitioners' willingness to treat adolescents with learning disabilities in the two contrasting geographical areas of EHSSB, Northern Ireland (NI) and NHSH, Scotland. Specifically, what factors would influence willingness to treat and what subsequent bearing would this have on accessibility to dental care for a group that is widely accepted as being underserved (RCSE, 2001; Band, 1998; Allison et al, 2001) and with poorer oral health (Crowley et al, 2005, Cumella et al, 2000; Gordon et al 1998; Nunn, 1987) compared with patients without disabilities?

Historically, the rigidity of accessibility research reflected the difficulties in providing a responsive health care service for people with disabilities. These models of accessibility located dental health problems firmly in the hands of the patient. But, a new means of viewing the concept of access was to emerge. In her FDI classification of Accessibility Factors, Cohen (1987) identified dental professional factors as one level within a three-tiered structure. This 'dental professional factor' level represented the need for appropriately trained dental personnel to connect with people's changing oral health needs and to be sensitive towards their attitudes and fears.

Thus the accessibility difficulties of any particular individual (with or indeed without a 'disability'), were no longer centre-stage. Instead, the FDI classification was seen as a planning framework that would allow Governments to set the scene and provide dental health care services (Freeman, 2002), which were to compliment the concept of normalisation that had been initiated in the previous decade.

And so began a long succession of White Papers, guidelines, reports and reviews, spanning the 1990's and early 2000's. Since the turn of the century, all four countries in the UK have produced major reviews of policies regarding services for people with learning disabilities (LD): The Same As You? (Scottish Executive, 2000), Valuing People (Department of Health, 2001), Equal Lives (DHSSPS, NI, 2005) and in Wales, Fulfilling the Promises (2002). But how effective has this rhetoric been? If the disparity in oral health status and treatment need between the disabled and the non-disabled remains huge (Cumella et al, 2000), is there perhaps another entity underpinning the spiralling waiting lists (DHSSPS, NI, 2002) and the adverse press reports, that have unfortunately now come to represent the reality of dental care for those with learning disabilities (particularly adolescents, identified as vulnerable within the context of "the transition years" (DoH, 2009) in some areas of the UK?

With this question in mind, Cohen's (1987) previously defined 'dental professional factors' were operationalised as a framework to consider access to primary dental

care, specifically for adolescents with LD, by exploration of the demography, knowledge, undergraduate and postgraduate experience, attitudes and service provision characteristics, of a representative sample of GDP's (employed in NHS and private practices) and dentists within the salaried dental service, with noteworthy results. The ensuing findings will be discussed.

6.2 The sample

The sample was deemed to be representative, with a valid response rate of 61%. The increased proportion of dentists employed within the salaried services in Scotland (61%) compared with Northern Ireland (49%) was not a surprising finding. The Scottish Dental Access Initiative (Scottish Executive, 2003), revisited in 2006 by the Review of Primary Care Salaried Dental Services in Scotland (NHS Scotland), sought to address the inequalities in the delivery of health care resources between rural and urban areas. Since Cohen (1987) has identified that 'manpower resources' are an accessibility factor within the dental professional level, it was, in fact, desirable that this difference was apparent in the sample. It facilitated a comparison of access to dental care between an area in which a larger proportion of the 'manpower' are not working under the time and financial constraints that are incumbent on dentists within the GDS, and another where it has been postulated that the extra time and/or staff requirements perceived necessary to provide treatment for those with LD, without reimbursement, creates a financial

disincentive to do so. This was the expectation for the majority of dentists working in NI.

6.3 Training in special care dentistry

6.3.1 Undergraduate training in special care dentistry

The fact that over three-quarters of the sample were found to have had no formal training at all in special care dentistry at undergraduate level is cause for concern. Furthermore, only 11% of dentists had benefitted from hands-on clinical experience for patients with disabilities. Since there were no significant differences in this startling statistic between the two areas of the UK surveyed, and given that nearly one third of the sample had received their undergraduate education outside of Scotland and NI, this would appear to be a worrying reflection of undergraduate education on a national basis.

Yet, the adequate delivery of special care dentistry at undergraduate level would appear to be universally problematic (Fenton, 1999; Romer et al, 1999). For example, Wolff et al (2004) have reported that half of fourth year dental students had never provided any treatment for patients with learning disabilities and more than a fifth indicated that they had had less than one hours' didactic teaching. It is of particular concern that lack of both confidence and clinical experience seems to be directly cited in relation to failure to treat patients with LD (Kane et al, 2008). In

keeping with the findings here, many primary care dentists acknowledged that the subject of learning disability received only cursory treatment in their undergraduate dental training. The majority indicated that they do not perceive that their undergraduate dental education had prepared them well to treat special needs patients in practice. The better dentists report to have been educated, the more likely they are to treat special needs patients (Loan et al, 2005). Similarly, 88% of undergraduates in dental schools across the UK and Ireland felt that they did not gain sufficient clinical experience in this area (Gordon et al, 2009).

Recent modifications in standards for dental education programmes have sought to reorganize and better prepare the next generations of practitioners to care for special care individuals in the primary care setting (to include those with LD), in acceptance that the *ad-hoc* nature of special care dentistry education failed to provide

> "*Sufficient exposure...to enable students to recognise their duty of care in the attainment of achievable treatment outcomes for patients…and to know the appropriate pathways for referral of patients whom they are unable to treat or require further assessment" .* (Thompson et al, 2001).

Although *The First Five Years* (GDC, 2002) had set learning outcomes, subsequently augmented by the British Society for Disability and Oral Health who provided a template for schools to revise their curricula (BSDOH, 2002) and benchmarking

standards have been set by the Quality Assurance Agency (2002) which echoed the thoughts of Thompson et al (2001), evidence suggests that most dental schools presently do not fulfil the requirements. (Gordon et al, 2009).

Yet, on a more positive note, the finding that undergraduate training experience was greater in the younger age group of respondents - more recently qualified dentists who have been exposed to revised curricula - is perhaps indicative of some level of success in this respect. So perhaps it is to be hoped that the present undergraduate dental education will better equip the future dentists to provide care for patients with learning disabilities: is it simply a case of 'time will tell'?

6.3.2 Postgraduate training in special care dentistry

Despite the result that only around one fifth of dentists had attended postgraduate courses on special care dentistry in the past, 85% were in favour of undertaking some additional training in the subject. This reflects the findings of Sota-Rojas and Cushing (1992), who found in their survey of dentists, that concerns were expressed about their confidence, competence, clinical skills and organisational skills in relation to managing patients with LD, with 70% believing postgraduate training to be the most favourable option for addressing these issues. In-service training, observation of other experienced clinicians in special care dentistry and continuing education courses, were opportunities that dentists expressed a wish to avail of. Other studies have mirrored these opinions (Erridge, 1986; Milnes et al, 1995;

Holland et al, 1996). Although the prevalence of such opinions in the current sample was lower among the GDS dentists compared with those in the SDS, sizeable proportions of dentists stated that they would welcome postgraduate training . This was the same for respondents in Scotland and NI, and whether they worked within NHS or private practices. It is unsurprising that dentists within the SDS are in greater favour of further postgraduate training than are dentists working in general dental practices, since most dentists working in the field of special care dentistry are based in the salaried dental services (Hunter et al, 2004) and, as Casamassimo (2004) points out, dentists who have already had hands-on experience in special care dentistry are more likely to desire additional training. This survey sample would concur with this view. Furthermore, treatment under general anaesthesia is largely under the remit of the SDS, and as such requires a set of skills in treatment planning and provision of care for patients that is beyond the working practices of dentists in the GDS. Comments made by Senior Dental Officers in a survey of dental services for patients with LD in NI (DHSSPS, NI, 2005), echoed these sentiments.

Consideration of general anaesthetic as a necessity for achievement of oral health, epitomizes one of the recurrent difficulties that health care professionals, including dentists, have for this group of patients. Apart from a general lack of understanding of learning disabilities within mainstream health services that has been identified, it has been suggested that health care professionals are not always conversant with the law around capacity and consent that relates to this vulnerable group of people

(Barr et al, 2006). Barr et al have further identified that health care professionals require training to understand disability itself and how to effectively establish an individual's method of communication to gauge their capacity to consent and what support is required to ensure that informed consent is obtained. This would seem particularly pertinent in dealing with the adolescent patient. Kerrins et al (2004) found that health care professionals in primary care believed that caring for people with LD was more difficult compared to other groups. This was attributed to lack of education and training pertaining to issues of communication. Cumella et al (2000) likewise referred to *"significant training issues in developing personal skills in total communication."* Although pockets of good practice are evident across the UK, (Martin and Martin, 2000), there remains misunderstanding around consent processes, with the result that many individuals with LD experience a further barrier when accessing health care services that they require. These studies would seem to add weight to the arguments proposed here that there is a need for increased provision of communication skills training, a fundamental recommendation of all policy documents and White Papers to date. Moreover, it is suggested that practitioners should avail themselves , of the formal training courses/programmes that are already in existence, such as those offered by the British Society for Disability and Oral Health, the British Society of Gerodontology, and Bristol University. It must, however, be borne in mind that on the whole, individuals who have undertaken training in special care dentistry, have been responsible for their own training (Gallagher and Fiske, 2007). The adverse

influence of student loans on new graduates' abilities to finance postgraduate training themselves must be recognised and addressed.

6.3.3 Current knowledge: Provision of special care dentistry

It was encouraging to note that levels of knowledge in relation to individuals with learning disabilities and provision of their dental care, was high for this sample, despite the respondents having indicated that they had received no formal knowledge-based course. It is of course possible that some knowledge has been interspersed within didactic teaching from other sources throughout the undergraduate curriculum, for example, tutorials or lectures relating to medically compromised patients. Following on from this is the finding, that for an as yet unknown reason, this form of education seems to take a more prominent role in shaping the knowledge base of female dentists in NI than their male counterparts, and compared with both male and female dentists in Scotland. This suggestion is, however, speculative and requires further research. Nonetheless, it is suggested that a cognitive dissonance may exist in this regard.

The literature would indicate that problems with lack of knowledge of learning disabilities, and/or oral health care for persons with disabilities, are reported as a barriers to providing care for special needs patients (Charteris and Kinsella, 2001; Christensen et al, 2005). Even in the wider health care arena, individuals with disabilities utilising primary preventive services have reported to feel that some

healthcare personnel lacked disability knowledge, held inaccurate preconceptions about people with disabilities and tended to view people with disabilities only through the lens of their disabling condition (Kroll et al, 2006). Loan et al (2005), meanwhile has postulated that knowledgeable staff are more likely to be comfortable treating special care patients and that this in turn is a crucial component of the dental team. In his survey of 500 dentists in Michigan, he did in fact find that the provision of a solid knowledge and skills base significantly improved their attitudes and confidence in treating this patient group.

Inadequate knowledge has therefore been cited frequently as a barrier (or a means of examining access according to Cohen (1987)) to receiving dental care. So the question that remains to be asked is this: does the simple transfer of information and acquisition of knowledge equate to dentists with more positive attitudes and willingness to treat adolescents with LD?

6.4 Service Provision

With an estimated prevalence of 2.8% of all young people (aged 13-25) having a learning disability in the UK (Mencap, 2004), there is no doubt that there exists a burgeoning population of individuals with learning disabilities, dependant on the community-based health care system for their medical and dental care. As a result of their integration into the community, coupled with improvements in medical care in the neonatal period, this figure will most likely be set to rise in the future.

Since it has been reported that the average NHS dentist working within the GDS will usually treat approximately 20to 30 patients per day, it is therefore a worrying statistic that one in five dentists in the sample, claimed to have not treated any adolescents with LD in the previous month.

This situation however is not unique to the UK. In a relatively recent US study, 70% of general dentists reported that they had never treated children with cerebral palsy in their practice (Cassamassimo et al, 2004). The query must therefore be addressed; is there a large proportion of people with LD living in the community who are unaccounted for due to a lack of comprehensive registers, or is this population being denied access to NHS primary dental care? This is of particular relevance in the context of care for the adolescent, who may be lost to follow-up if a system has not been put in place at the transition period of school leaving.

It was to be expected that dentists working in the SDS would report treating larger numbers of adolescents with LD than those dentists in the GDS. During the 1990's, many general dental practitioners left the NHS because of changes in contractual arrangements and remuneration. It was thought that this had the effect of reduced availability of NHS dentistry in general, whilst simultaneously placing an increased demand on the SDS. Thus, the SDS came to have a 'safety-net' role (Freeman, 1997). Furthermore, it is accepted that a proportion of patients with LD will require GA or sedation for some items of their treatment (Graham et al, 2007): it is

possible that this concern overrides the decision to even attempt treatment under local anaesthesia, thus circumventing any real or perceived behavioural difficulties. Like wise, the increased numbers of patients treated by NHS dentists compared with private dentists in the GDS, reiterates one of the fundamental problems associated with providing care for this group: that many dentists are unwilling to treat the individual with LD because of the inability to obtain fees commensurate with the time and effort that must be invested to successfully undertake treatment in the dental chair under local anaesthetic. After all, it could be argued, that in the realm of other specialties in community care such as orthodontics or oral surgery, there are financial and professional incentives for general practitioner involvement. Does this approach support the idea that adequate financial remuneration is a more realistic path to addressing the problem of access to care and spiralling waiting lists for treatment under general anaesthesia?

It is a recurrent theme in the literature to date that female dentists are more inclined to treat special care patients than are their male contemporaries. This, too, was reflected in this survey sample, with significantly larger proportions of female compared to male dentists treating more than 5 adolescents with LD in the previous month. It has been found, both historically (Yuker, 1960; Garmanikov, 1978; Furnham et al, 1983) and in more recent studies (Brillhart, 1990; Paris, 1993; Coyle et al, 2004) that women have more positive attitudes towards individuals with disabilities and are less likely to hold prejudicial views towards those who are disabled. Moreover, Higgs (1972) and Paris (1993) have found that women with

frequent contact have significantly more positive attitudes towards people with disabilities than do women with less frequent contact. There is perhaps some merit then in considering the impact of frequency of contact with individuals with LD on attitudes willingness to provide dental care.

Interestingly, greater levels of undergraduate experience and knowledge levels in this sample of dentists did not correlate with increased numbers of adolescents with LD having received treatment in the previous month. This supports the earlier supposition that the respondents do not necessarily act on the knowledge or desirable social response that they are likely to be aware of. Furthermore, undergraduate experience and level of knowledge had no bearing on the likelihood of a dentist in the sample providing IHS, appointment scheduling, wheelchair access, emergency care information and access to the services of a hygienist.

6.4.1 Provision of special care services

Whilst undergraduate experience and level of knowledge were not related to provision of special care services by dentists, area of work was found to be important in this respect, supporting Cohen's accessibility factors.

It is well recognised that young people in rural areas have difficulty accessing dental care (Vargas et al, 2003). It has been said that compared to parents from urban areas, rural parents report that their children have greater unmet needs for dental care, experience longer gaps between visits and have more untreated caries

(Waldman, 2002; Byck et al, 2002). Unsurprisingly, the rural location of NHSH was reflected in the distances that patients reported that they had to travel to access IV sedation, GA and specialist facilities. Yet, despite this, there is no evidence to suggest that waiting lists for treatment are longer or unmet treatment needs greater, for adolescents in Scotland compared with NI. (Hally and Freeman, 2009).

Perhaps as a result of the absence of a specialist hospital dental service to refer patients to, larger proportions of dentists in Scotland had wheelchair access and availability of the services of a hygienist in their surgeries, compared with dentists in Northern Ireland. It could be proposed that in NI, it is easier to circumvent the Disability Discrimination Act (DoH, 2005) through the caveat of availability of an 'alternative' provider, via referral to the secondary care service in Belfast which is within a 'reasonable' distance of all dental surgeries within the EHSSB area. This is evidently not an option in the rural setting of Highland, which is the size of Belguim.

The increased prevalence of use of the skills of dental hygienists in Scotland was encouraging, as has been identified as being pivotal to the provision of preventive programmes for people with LD and their carers (Gallagher and Fiske, 2007). Although there has been identification in NI of the need for *"a skill mix balance in each Trust to facilitate prevention…including staff recruitment of oral health promoters and dental hygienists"* (HSSPS.NI, 2005), there is a paucity of evidence to suggest that this ideal has come to fruition yet nor that the inequitable distribution

of the small numbers of existing dental hygienists throughout the EHSSB area has been addressed.

6.4.2 Intention to treat

The intention of dentists to treat adolescents with varying severity of LD, was found to follow a similar pattern to that which emerged for provision of special care services, in that a 'needs must' approach in the absence of a convenient alternative, became apparent. For example, dentists in Scotland intended to treat adolescents with severe LD; in NI, treatment for these patients historically have been viewed as the remit of the Specialist Hospital Dental Services and this legacy has persisted to a large extent. Similarly, dentists within the SDS intend to treat all levels of LD, most likely explained by the fact that ordinarily, special care patients form the cornerstone of their workload. As was noted in respect of numbers of adolescents with LD treated by dentists in the previous month of work, undergraduate experience had no impact on intention to treat this group of patients. It is, however, more difficult to explain the effect of knowledge on intention to treat adolescents with LD. Whilst level of knowledge had no bearing on actual numbers of patients with LD treated per month, greater levels of knowledge were associated significantly and positively with intention to treat adolescents with LD of all levels of severity. It could be suggested that the simple task of information acquisition with regard to the nature of learning disability and its' clinical management in other words the 'medical model' of disability, inevitably improves knowledge about the

condition and dental treatment thereof. Alongside this 'ideal' is the notion of 'ideal' intentions. However, with the day to day reality of the clinical practice of dentistry and its associated stresses, may come the failure for these 'ideals' to translate into the actuality of treatment provision for those with learning disability.

6.4.3 Willingness to treat

It is clear that willingness to treat is a multi-faceted concept. In this sample of dentists, it is notable that neither undergraduate experience, nor knowledge level, had an obvious direct effect on number of adolescents with LD who are actually treated in a defined period of time. Yet, it would appear contradictory that level of knowledge does seem to have a role to play in *intention* to treat. So what other factor(s) are interacting to contribute to dentists' willingness to treat adolescents with LD in primary care if these two entities are excluded?

A combination of the variables examining intention to treat, confidence to treat, want (desire) to treat and stress associated with treating adolescents with disabilities, was found to provide a scale with good reliability for the sample. Although the variables of gender and age-group of dentist, (more specifically, younger dentists in Scotland) demonstrated interactions, these failed to shed any further light on the dentists' willingness to treat and thus improved accessibility to dental care for adolescents with LD.

It was therefore concluded that some additional underlying factor, perhaps more specific to the individual but independent of demographics or transfer of information, must be contributing, or indeed inhibiting, willingness to treat adolescents with LD. Could the answer lie in the attitudinal dimension of willingness to treat?

6.5 Attitudinal dimension

An attitude is a disposition or feeling towards a person or thing (Peat, 1997). In the health care profession, a clinicians' attitude towards a patient or situation is important, because prevailing attitudes and misconceptions can be potential barriers to both ability to access care and successful treatment (Antonak and Livneh, 2000). Negative attitudes towards persons with disabilities are a product not only of individual beliefs, but also of societal and organisational practices (Yuker, 1965; Claxton, 1994).

In consideration of the societal and organisational elements of attitudinal dimensions for this sample, by use of Bedi's (2001) attitudinal scale questionnaire, several significant differences were apparent between the areas of work, gender and age-groups of the dentists for individual questionnaire items and total mean scores. However, subdivision of Bedi's (2001) attitude scale into 2 principle components, allowed for a greater understanding of the dentists' own attitudes

and beliefs and hence the subsequent implications for their willingness to treat adolescents with LD. The first component, or 'clinical factor scale' referred, as its name would imply, to the medical and clinical aspect of dental care: the practicalities of 'getting the job done' – the equipment, the time, the effectiveness that must be employed in the dentist-patient interaction, to complete an item of treatment as efficiently as possible. On the other side of the coin however, is the second component; the 'social factor' scale. This reflects a dentists' ethos on an inclusive society, equitable care, human rights of those with disabilities: in other words, the social context of where individuals with LD fit into a model of dental care.

The traditional way to view disability, of any nature, is to see it simply as a medical problem. By approach, disability and the ensuing problems arise as a result of impairment. This medical model is the basis for medical/dental treatment of individuals with disability, and has been the philosophy of the undergraduate dental curriculum (The First Five Years, GDC, 2002). In this way, the disabled person becomes the centre of attention; the focus is on changing the individual, usually through the medical modification of their impairment. The implication is that the fortunes of those with disabilities lie in the hands of the medical/dental profession, according to their definition of what that individual needs – normative need (Bradshaw, 1972). Hence, the autonomy of the 'disabled' person is removed. Additionally, the medical model presents the environment as 'neutral' and stable. The onus is on the individual to adapt, adopt coping strategies, and limit their own

hopes and ambitions (Barnes, 1999). This would appear to echo the perspective of the 'clinical factor scale'.

An alternative approach is the social model of disability described by Oliver (1990). This model argues that it is society that disables people with impairments by its failure to include them. It is social, cultural and environmental barriers that lead to the oppression of those with disabilities, with attention being directed away from the individual's impairment. Consequently, a change in society and not the individual ameliorates the disability. This model, which encompasses human function at the bodily, personal and social level, is fundamental to the 'social factor' scale. It may be proposed that this perspective is contributory to the development of more positive attitudes of undergraduate dental students, thereby translating into their willingness to treat adolescents with LD (or indeed any individual with a disability).

It was noted that male dentists and those dentists in the older age-group, scored more highly for 'clinical factors' and female dentists for the 'social factor' items. This would imply that the perceptions of LD for male dentists and those in the older age-group disabilities are rooted firmly in the medical model. The social model of disability however underpins the beliefs and attitudes of female dentists. It can therefore be proposed that females and younger dentists hold more positive, socially inclusive attitudes towards individuals with LD. Area of work had no bearing

on the likelihood of dentists to view LD through the lens of either the social or the medical models of disability.

It is widely accepted in the literature, as has been found in this present survey, that females hold more positive attitudes towards individuals with disabilities than do males in all fields of health care, as discussed. Likewise, it has been well recognised that the enthusiasm and positive expectations of dentistry in more recently qualified dentists can become eroded by the increase in cynicism known to occur as their career develops (Kinne and Stiefel, 1979). Personal socialization may also have an effect, with the progressive loss of idealism (Devlin et al, 1994). However, it could also be proposed that for this sample of dentists, the younger age group are more likely to have been exposed to some form of special care dentistry specific training than their older contemporaries, thus entering primary care with some grounding in this area of work.

So what forces, then, are at work to influence willingness to treat, and how do they interact to produce a dentist in the primary care setting who is willing to treat adolescents with LD, irrespective of financial remuneration, rural location and availability of special care dental services? We can accept that area of work, *per se*, is not a significant factor in this respect. In other words, what is the relationship between knowledge, undergraduate experience, social or medical model ideals of care and willingness to treat?

6.6 Predicting willingness to treat: a path analysis

The model was constructed in a bid to understand the interaction of these factors. The interpretation of the model was as follows. The variable 'clinical factors' was strongly related to willingness to treat in a negative direction. This demonstrated that those participants that regarded the delivery of care using a more medically orientated approach were less likely to be willing to treat learning disabled patients. The social factors scale was also related to treatment willingness, although the association was positive but of less relative magnitude to the clinical factors scale. Social Factors scores were strongly negatively associated with clinical factors. The direction of influence was indicated as the participants with greater social factors scores holding less strong beliefs about the adoption of a medical orientated approach to dental care. It was considered that participants with greater social factor scores would hold these beliefs prior to their opinions about a medically orientated approach being developed. It is of course possible that this indication of direction may be the reverse.

Knowledge had a moderate positive effect on social factors. Moreover the training level achieved at undergraduate level was marginally related (negatively) with clinical factors and positively associated with social factors. Notably knowledge had no reliable effect on clinical factors. Hence, knowledge of LD and undergraduate experience through the pathway of 'social factors' meant that practitioners were

more likely to have a greater propensity for willingness to treat adolescents with LD.

Therefore the significance of undergraduate education on willingness to treat and access to care is important. Yet controversy exists as to how exactly this problem should be addressed. There is little doubt that reliance upon the medical model fails to provide adequate 'useable' knowledge for dental students. A further failure of the medical model is its functional uselessness in assessment of management problems; characteristics and severity of conditions which have no consistent relationship to dental management problems. Also, the medical model deals poorly with mixed disorders, more likely to present in practice (Casamassimo, 1983). In Casamassimo's words; "*the medical model is a crutch for educators and students in the classroom, but is of little functional value".*

In the USA and in response to recognition of the limitation of the medical model, educational programmes were developed within universities. These, too, were not without problems. One approach was that of didactic programs. In Casamassimo's opinion, these provide too much information, that if retained, serves mainly to confuse. Schuchman (1984) agreed; it is unreasonable to expect a series of classroom presentations to prepare dental undergraduates to cope with the challenges of a patient with learning disabilities. This would seem to provide a

plausible answer as to why the practitioners in this sample were unable to utilize their knowledge and treat adolescent patients with LD.

Does the answer to promoting positive attitudes then lie in educational programs that assume an active role? Numerous studies have indicated that fear and anxiety due to lack of experience in the undergraduate dental curriculum, promoted negative attitudes towards treating those with learning disabilities; once students gained experience, this fear and anxiety decreased markedly (Block and Walken, 1980, Campbell and Mc Caslin, 1983). Furthermore, Casamassimo (2004) found that those dentists who had both hands-on and lecture experiences were significantly less likely to perceive a patients' level of disability or their level of training as barriers to their willingness to treat them as compared to practitioners who had lecture experiences only.

However, Miller and Heil (1976) showed that these courses must be well designed if they are to make a positive impact. Mere exposure of dental students to those with learning disabilities does not in itself produce positive attitudes. The course must be well-structured, with the co-operation of several specialities. If insufficient support is available, frustration and negative reinforcement will be promoted among the students (Bedi et al, 1986). In Bickley's (1990) opinion, visiting day-care facilities for those with learning disabilities living in the community is a much more valuable and less traumatic introduction for the inexperienced and apprehensive student. It is

also more conducive to the concept of community care and hence the promotion of a social model of disability.

It has therefore been suggested that while undergraduate educational programmes improve awareness and may change attitudes, in the long term they do not appear to affect the percentage of dentists that will be willing to treat those with learning disabilities. Intensive programs show an average increase of only about 6 – 7% in graduates who actually engage in treatment (Casamassimo, 1983). This 'baseline' of students may have a personal interest in those with learning disabilities, as a result of personal contact or practical experience. The growing concern is that even those students with a propensity to care may be 'lost' in an environment that is not conducive to the development of their personal qualities. Meanwhile, the educational experience has only served the purpose of strengthening the resolve of those who have already a vocation or altruistic motives to provide care for the underserved in the community.

So does the nature of the contact between the patients with a disability and the undergraduate/postgraduate dentist play a part? What quality component of training is 'missing' from the undergraduate curriculum that is failing to 'engage' the student, and foster their interests and empathy once this has tentatively been established?

One such educational intervention that has been suggested in the medical profession as being conducive to the development of positive attitudes is that of equal-status contact (Geskie and Salasek, 1988). Wright (1980), too, has noted that where the setting shows a person with a disability functioning in terms of their capabilities (ie; equal-status), attitudes are more likely to be favourable than in settings that highlight the person's inadequacies and disabilities. Or perhaps put another way in the context of more recent literature, in the social model setting. This could include creating familiar rather than casual contact with patients with disabilities, having parents of children and teenagers with a disability share experiences, or having the opportunity for individuals with a disability to act as teachers. It is important that students have role models who demonstrate positive attitudes towards persons with disabilities. These role models may be their clinical mentors or other community members with whom they may interact outside of training. As students begin to recognise the vocational relevance of caring for a person with a disability, this deeper style of learning may lead to a more profound and long-lasting change in attitudes.

6.7 A search for solutions

There is undoubtedly an irrefutable need amongst practitioners for increased knowledge, abilities, positive attitudes and willingness to treat, in respect of adolescents with LD. But in an effort to enhance the dental profession's ability to respond and meet the needs of this population, sight cannot be lost of the reality

that the norm for other specialties is for the burden of providing the major component of care to fall upon the general practitioner.

Some practitioners who work with patients with disabilities, anecdotally, estimate that most with mild or moderate disabilities are treatable by general dental practitioners in primary care. And in the context of normalisation, they should *theoretically* have little difficulty in accessing mainstream primary dental health care.

It is anticipated that the establishment of the Special Care Dentistry specialty by the GDC, will encourage dentists with an interest in this field to embark on a career in special care dentistry. Thus it is hoped that the development of a structured workforce will help meet the oral health care needs of those with LD. But since the 'norm' of the GDS acting as the major component of care provision for this group does not appear to apply , will the establishment and development of this new specialty only serve to reinforce the sentiment of "let someone else do it" (Waldman and Perlman, 2002)?

General dental practices offer advantages that include continuity of care, the opportunity to access mainstream service, a wider choice of service providers, and the convenience of location that a specialist centre may not have. Added to this is

the fact that research has shown that people with disabilities vary in their views of the type of service they want: whilst some may want the option for more specialist facilities, others will prefer mainstream services (Kaye et al, 2005).

So how can these service providers be amalgamated to address the general issue of unmet need and more specifically, the problems inherent to dental care for the adolescent patient, for whom the transfer from paediatric to adult services (with the associated risk of loss in the 'system' during this transition period) can occur as early as age 13 in some centres? Indeed, parents of patients with Down Syndrome expressed their wishes to have people with disabilities treated with the same standards as people without a disability and that they desire good access to mainstream dental services with the support of expert pr specialist advice and facilities as required (Kaye et al,2005). Does the key to the solution of these problems then lie in this sentiment?

It has been proposed that the concept of managed clinical networks, which seems to reflect the ideal of parents' identified by Kaye (2005), may provide an answer.

Managed clinical networks (MCN's) are self-supporting groups of professionals working together to ensure cross-speciality sharing of patients and expertise. They are a strong mechanism for ensuring that patients receive the care they need in a

timely fashion from the most suitable professional in the network area (Skipper, 2010). MCN's work by bringing together dentists with a special interest in working in primary care, with specialists working in secondary care, thereby making the referral process smoother and less cumbersome. If operating fully, a MCN should strive to cover all aspects of primary and secondary care, thus maximising patient access. However, it differs from a regular clinical network in that it must work to outcome measures and also involve patients in its' formulation and establishment. In this patient-centred, holistic manner, it is anticipated that traditional barriers to accessing care will be broken down and quality of care for this group of adolescents improved.

A MCN would offer clinicians of all levels of experience an opportunity to work in a more constructive and supportive environment and ensure that their skills are kept up to date. Specialised or more experienced colleagues (specialists and dentists with special interests) can guide and assist more junior colleagues who wish to develop their skills in a new area, or indeed learn how to correctly identify when additional support or expertise is required. By this means, only those at the complex and of the spectrum of disability will require specialist care on an ongoing basis. It would be expected that routine, regular dental care for those with mild and moderate LD could be provided by the GDS and SDS, augmented by the underused and complimentary skills of dental nurses, hygienists and possibly community LD nurses. For instance, LD nurses are known to have a range of observational and communication skills which could usefully be taught to other health care

professionals (Cook, 1998). Yet, community LD nurses are an untapped resource in assessing the health needs of , assisting access to and co-ordinating care for adolescents and young adults with LD in primary care (Thornton, 1996). More importantly, they are a vital link in chain of professionals in both the medical and educational settings and as such, may be a crucial in targeting adolescents in the transition years as they are discharged from paediatric services, through liaison with schools, parents, and both hospital and community paediatricians.

So could a fully functional MCN achieve the ideal outcome of equitable access to dental care for adolescents with LD, a decrease in unmet need and management of the 'congestion' that presently exists at the secondary care level?

It is perhaps the patient-centred concept that is the crux of the establishment and management of a primary care dental service for those with LD. It has been suggested that that there is

> "*Too much conceptualising of disability and not enough emphasis placed upon the research from the perspective of people with disabilities themselves".* (Shakespeare, 2006)

Others agree: people with disabilities should be involved and participate in the delivery and teaching of continuing education programmes (Kroll et al, 2006). Participants in Kroll's study further stated that they felt health care professionals

trained by consumers with disabilities would be better equipped to communicate and work with patients with disabilities; *"I'm not treated as a very smart individual with anything important to say"*, was cited as a specific example. The theme of consumers educating their healthcare providers in their medical care needs, disability etiquette and communication needs would facilitate integration of the social model of disability firmly within the ethos of the MCN , ensuring that positive attitudes introduced in the undergraduate years become further embedded as students progress to working in primary care. The continuation of any 'equal-status' encounters in the early years needs to be frequently reinforced, thus a spiral curriculum for undergraduate dental students can be developed (Coyle et al, 2004).

Perhaps the value of the inclusion of people with disabilities in the delivery of curricula dental care consistent with the social model of disability is best summed up as follows:

> *"There needs to be an educational component, and I really believe that disabled people need to go in and teach the healthcare people what they simply do not know. They don't know and they are so busy and so rushed that they won't stop and learn it. It needs to be part of their educational component. Somewhere in there."*
>
> [Views of a participant in a study by Kroll et al (2006)]

6.8 Limitations of the study

The cross-sectional design of this study of this study is a fundamental limitation. Longitudinal studies assessing the effect undergraduate and postgraduate training, clinical experience and changes in service provision and fee structures, on the attitudes and willingness to treat scores of dental professionals over time are necessary. This would allow a full understanding of how attitudes towards individuals with learning disabilities are created, fostered, sustained and, most importantly, maintained.

Whilst the response rate to the survey was on the lower end of that defined as acceptable(61%), the level of response is however equal to the average achieved for postal questionnaires of general dental practitioners across 42 published reports surveyed by Tan and Burke (1997). The lack of response lends support to the possibility that the rate may be due to a disinterest in the subject matter, thereby reflecting less positive attitudes towards those with disabilities. This inevitably raises the question that the survey sample may not represent the population adequately with respect to dental professional attitudes towards individuals with LD, and may be biased towards more favourable attitudes.

Previously researched scales for measuring attitudes towards people with disabilities have been criticised for their unequal balance between positively and negatively worded statements, the use of double negatives, and because some

items fail to distinguish between high and low scorers (Furnham and Pendred, 1983; Speakman, 1989). However, the Bedi (2000) scale used in this survey was found to have good internal reliability and consistency for this sample of qualified dentists.

It is acknowledged that willingness to treat may not necessarily translate into actual dental treatment. In a New Mexico study of dentists, 90% reported that they would be willing to treat patients with disabilities. However, their willingness varied according to the type of disability. For example, dentists were more willing to treat a patient with epilepsy than a patient with learning disabilities (Siegal, 1985). This study also highlights that patients with disabilities are not a homogenous group. This must be borne in mind when considering the responses to the attitude questionnaires; specifically that a respondent may select an alternative answer depending on the level or specificity of the disability. It is impossible to take account of this potential variation in the analysis, but the author is of the opinion that the 2 questionnaires (Bedi, 2000; Coyle et al, 2004) measured a generalised attitude towards disabled individuals as a group. The emphasis is placed on the differences between disabled and non-disabled people and the 2 scales reflect these perceived differences. In this way, a reasonable assessment of attitudes towards people with disabilities can be achieved.

The path analysis was performed to provide some clarity and ease of exposition of how willingness to treat can be predicted. It is accepted that there are many different models that could have been applied and tested. A backward stepwise approach to the modelling was applied and this does have some dangers that the final model chosen may not be as generalisable due to one or more of the paths being retained as significant by chance. However the accusation of generalisabilty can be reduced in strength as the model appeared to fit the two sub samples from different countries in the UK without significant disparities. It is admitted that sample size was moderate and the precision of the modelling would have been improved by a larger sample size.

7.0 Conclusion

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Through consideration of Cohen's (1987) Accessibility Factors at the dental professional level, the issue of unmet treatment needs for adolescents with LD has been found to have many dimensions. For this sample, willingness to treat adolescents with LD was positively associated with a social model perspective on disability. This in turn translates to the development of positive attitudes. Conversely, dentists who hold a medical model of disability, as demonstrated by clinical factor scoring, were found to have more negative attitudes and were less willing to treat adolescents with LD.

The acquisition of knowledge and increased level of undergraduate training in relation to LD and its' management would appear to strengthen a social model perspective and hence promote positive attitudes and willingness to treat those with LD. Meanwhile, undergraduate training and knowledge pertaining to disability did not significantly contribute to dentists whose beliefs underpinned the medical model of disability. These findings were consistent for both dentists working in 2 distinct areas of the United Kingdom. Therefore area of work *per se* (ie rural or urban location) is not an influential factor in willingness to treat and hence unmet treatment need. This does not exclude the possibility that area of work may have a bearing on willingness to treat as a function of university attended for their undergraduate training.

The Darzi review of the NHS (DoH, 2007) highlights a shift in national policy, from a limited selection of health and social care services to a mainstream system. For the provision of oral healthcare for people with disabilities, this will necessitate dental service providers to work in new ways. Perhaps the most appropriate method of bringing this to fruition is to use extended teams which take responsibility for educating that team in how to incorporate oral health into the holistic care of each individual with a disability. Positive attitudes allow dentists to think about overcoming obstacles which presently result in unmet dental needs.

With this question in mind, Cohen's (1987) framework is a helpful tool in devising a trained workforce and perhaps the ultimate goal of a functioning managed clinical network, providing an equitable service for all.

Health professionals are only too aware of the difficulties that individuals with LD and their relatives have in accessing opportunities for simple everyday choices. Often these battles must be negotiated by articulate, tenacious parents (perhaps with their own health problems as they approach old age), leaving behind the even more vulnerable who are further disadvantaged by their educational, family and social isolation, ostracised from local communities and left to flounder alone. While much attention has been drawn to the issues of employment and housing for adolescents with LD in recent years, the basic rights and choices such as access to dental care, have been somewhat neglected. Surely healthcare of this type should not be viewed as a privilege for individuals in this age group with learning

disabilities and their families, but rather a right: all too often this does not seem to be the case.

There could be not be a more stark reminder of this fact than the Health and Local Government Ombudsmen recent published findings on the events surrounding the deaths of six people with LD who died in NHS care, highlighted by Mencap's (2007) "Death by Indifference" report . This revealed;

> *"significant and distressing failures…poor care….quality of care in the NHS and social services for people with learning disabilities is at best patchy and at worst an indictment of our society".*
>
> (Mencap, 2007)

The report recommended that NHS and social care organisations urgently review the effectiveness of the systems and services they have in place.

And so to consider this in the context of primary dental care: This survey has sought to understand and demonstrate the complexities of dentists' willingness to treat individuals with LD in the primary care setting.

It can be suggested that willingness to treat adolescents with LD is positively associated with a social model perspective on disability. This in turn translates to the development of positive attitudes and is further strengthened by acquisition of knowledge on the subject matter and suitable undergraduate training. Dentists who hold a medical model of disability are found to have more negative attitudes and are less willing to treat adolescents with LD. These beliefs appear to be more ingrained and less amenable to change through traditional didactic teaching approaches.

If the medical model continues to form the cornerstone of undergraduate dental training, with limited opportunities for hands-on treatment of those with LD and no attempt to make room for the experiences and views of individuals with disabilities, will negative attitudes continue to plague the health care profession and society at large? It seems that the political aspirations of pursuing a more inclusive project such as “Valuing People” (DoH, 2001), in which the promotion of rights, choice and independence were documented, became eclipsed by the professional recognition of need. There appears to be a persistence of the medical model and thus, by implication, professionals have a role in ‘treating’ what Oliver (1996) defines as a social product. This problem clearly needs to be tackled at the undergraduate level.

Just as this survey began with a narrative review of the historical perspective of LD, it is perhaps fitting to conclude with the reflections of Frewin (2009), an able bodied

woman with learning disabilities who lives alone in sheltered housing. Once again, the lessons of the past have been lost in a healthcare system which fails to meet the needs of those with LD:

> *"Valuing People did not do what it needed to do, it was all really exciting but has not lived up to the expectations..I felt that I was not making a difference because the changes that I suggested were not always acted upon. … My aspirations for the future are for the Government to take more responsibility for helping us access services…As part of that the more people with intellectual disabilities need to have the opportunity to tell their stories to help others understand what our lives are about".*
>
> (Frewin, 2009)

8.0 Recommendations

8.0 Recommendations

The recommendations suggested as a result of this survey of access to dental care for adolescents with LD are with a view to improving the knowledge, attitudes and behaviour of dentists in primary care. It is hoped that these would address the issue of unmet treatment need for this group of patients.

1. Undergraduate education

    - Early exposure to people with a learning disability in the community setting must be to be incorporated into the first years of the undergraduate programme.

    - The equal-status concept of contact with people with LD should be developed, thus taking the viewpoint of the individual with LD, their carers and their families into consideration.

    - Students must gain 'hands-on experience' by treating patients with learning disabilities. This experience should be frequent to reinforce the need for mainstreaming of treatment of patents with LD in primary dental care.

    - Didactic components of the programme should stress the social model as opposed to the medical model of disability**.**

2. Postgraduate education

    - Postgraduate educational systems should facilitate the development of managed clinical networks, with opportunities for primary dental care practitioners with an interest in treatment of those with LD, to have the support and guidance they need to develop their skills.

    - Mainstreaming of dental care for those with LD should be reinforced. Training should allow dentists who do not wish to treat those with LD themselves, to make appropriate referrals to dentists with special interests, specialists and hospital consultants. Similarly, further training will streamline the referral process between each tier of the managed clinical network, with an aim to have an equitable distribution of services.

9.0 References

9.0 References

1. Albrecht G (1992). The Disability Business: Rehabilitation in America. Sage Library of Social Research, 190. London.
2. Allison PJ., Hennequin M (2000). The oral assessment in Down syndrome questionnaire (OADS): development of an instrument to evaluate oral health problems in individuals with Down syndrome. *Community Dental Health*. 17:172-179.
3. Allen D., Tynan H (2000). Responding to aggressive behaviour: impact of training on staff members' knowledge and confidence. *Mental Retardation*, 38: 97-104.
4. Allison PJ, Faulks D, Hennequin M (2001). Dentist-related barriers to treatment in a group of individuals with Down syndrome in France: implications for dental education. *Journal of Disability and Oral Health*; 21:147-152.
5. Antonak RF., Livneh H (2000). The measurement of attitudes towards people with disabilities. *Disability Rehabilitation*; 22(5):211-24.
6. Arbuckle J (2008). Amos 17 User's Guide. In: (17.0 ed.) Spring House. Amos Development Corporation.
7. Arscott K., Dagnan D., Stenfert Kroese B (1999). Assessing the ability of people with a learning disability to give informed consent to treatment. *Psychological Medicine*, 29: 1367-1375.

8. Atherton H (2007). A history of learning disabilities. In: *Learning Disabilities: toward inclusion.* Gates B (Ed). Elsevier: London.
9. Atkinson D, Jackson M, Walmsley J (Eds) (2007). *Forgotten lives – exploring the history of learning disability.* British Institute of Learning Disabilities publication. Cookley Printers. Worcestershire.
10. Band R (1998). The NHS – Health for all? People with learning disabilities and health care. London: Mencap.
11. Barnett ML, Press KP, Friedman D, Sonnenberg EM (1986). The prevalence of periodontitis and dental caries in a Down's syndrome population. *Journal of Periodontology;* 57: 288-293.
12. Barker (1998). Employability in the North? A good business practice for North East employers on the employment of disabled people. Disability North.
13. Barnes C (1992). Disabling imagery and the media. The British Council of Organizations of Disabled People. Ryburn Publishing Ltd: Halifax.
14. Barnes (1994). Disabled people in Britain and discrimination: A case for anti-discrimination legislation. Hurst and Company in Association with BCODP: London.
15. Barnes C, Mercer G (eds) (1996). Exploring the divide. The Disability Press: London.
16. Barnes C, Mercer G, Shakespeare, T (1999). Exploring disability: A sociological introduction. Policy Press: Cambridge.
17. Barr O (2006). When two worlds collide. In: *Royal College of Nursing Annual Learning Disabilities Conference*. London.

18. Bateman P, Arnold C, brown R, Foster LV, Greening S, Monaghan N, Zoitopoulos L (2010). BDA special care case mix model. *British Dental Journal*; 208:291-296.
19. Batty D (2004). The Guardian Newspaper, 24th November 2004.
20. Bedi R., Chan C., O'Donnell, D (1986). Evaluation of attitudes of Chinese dental students toward dental care for patients with handicapping conditions. *Special Care in Dentistry,* Jan/Feb 29-33.
21. Bedi R, Champion J, Horn R (2000). Development of an attitudinal scale for dental personnel in the provision of care for people with learning disabilities. *Journal of Disability and Oral Health*; 1:26-30.
22. Bedi R, Champion J, Horn R (2001). Attitudes of the dental team to the provision of care for people with disabilities. *Special Care in Dentisry*; 21(4): 147-152.
23. Bickley, S (1990). Dental hygienists' attitudes towards dental care for people with a mental handicap and their perceptions of the adequacy of their training. *British Dental Journal,* 168:361-364.
24. Block, M., Walken, J (1980). Effect of an extramural program on student attitudes toward dental care for the mentally retarded. *Journal of Dental Education,* 44, 3: 158-161.
25. Bollard M, Dukes MJD (2009). Specialist practitioner within community learning disabilities and the primary health care team. *Journal of Learning Disabilities;* 3(1): 11-19.

26. Borthwick C (1996). Racism, IQ and Down's Syndrome. *Disability and Society* 11(3): 403-410.

27. Bradshaw, J (1972). A taxonomy of social need. In: *Problems and progress in medical care.* McLachlan, G (Ed) (1989). Seventh series. Oxford University Press: Oxford.

28. Bredberg E (1999). Writing disability history: problems, perspectives and sources. *Disability and Society;* 14(2):189-201.

29. Brillhart B (1990). Attitudes toward people with disabilities. *Rehabilitation Nursing;* 15:80-85.

30. BSDOH (2002). Guidelines for the oral health care for people with mental health problems. Report of the BSDOH Working Party. BSDOH. London.

31. Burke FJT, McCord JF, Hoad-Reddick G, Cheung SW (1995). Provision of domiciliary care in a UK urban area: results of a survey*. Primary Dental Care*; 2: 47-50.

32. Bury M (1996). Defining and researching disability: issues at stake. In: *Exploring the divide*. Barnes C, Mercer G (eds) (1996). The Disability Press. Leeds.

33. Byck GR, Walton SM, Cooksey JA (2002). Access to dental care services for Medicaid children: variations by urban/rural categories in Illinois. *Journal of Rural Health*; 18:518-520.

34. Campbell NA (2003). Aspects of a service for people referred for routine dental treatment with general anaesthesia or sedation. Oral Health and Disability: The Way Forward. *National Disability Authority.* Dublin.

35. Campbell J., M^{c}Caslin, C (1983). Evaluation of a dental training program for care of the handicapped. *Special Care in Dentistry,* May/June 100-107.
36. Carvel J (2007). The Guardian Newspaper. December 3rd 2007.
37. Casamassimo PS, Seale NS, Ruchs K (1994). General practitioners' perceptions of educational and treatment issues affecting access to care for children with healthcare need. *Journal of Dental Education;* 68(1): 23-28.
38. Casamassimo, P (1983). The great educational experiment: has it worked? *Special Care in Dentistry,* May/June 101-106.
39. Charteris P, Kinsella T (2001). The oral care link: a facilitator and educator for maintaining oral health for patients at the Royal Hospital for neurodisability. *Special Care In Dentistry*; 21(2): 68-71.
40. Children (Northern Ireland) Order (1995). Belfast.
41. Children (Scotland) Act (1995). Edinburgh.
42. Christensen LB, Hede B, Peterson PE (2005). Public dental health care program for persons with disability. *Acta Odontologica Scandinavia*; 63(5): 278-283.
43. Chubon RA (1982). An analysis of research dealing with the attitudes of professionals toward disability. *Journal of Rehabilitation*; 48(1):25-30.
44. Clarke D (1986). Mentally handicapped people living and learning. Bailliere Tindall: London.
45. Clark C, Vanek E (1984). Meeting the health care needs of people with limited access to care. *Journal of Dental Education*, 48: 213-216.

46. Claxton A (1994). Teaching medical students about disability. Editorial British *Dental Journal*; 308:805.

47. Clegg JA, Standen PJ, Cromby JJ (1991). The analysis of talk sessions between staff and adults with profound intellectual disability. *Australian and New Zealand Journal of Development Disabilities*, 17:391-400.

48. Cohen L. Converting unmet need for care to effective demand. *International Dental Journal,* 1987; 37:114-116.

49. Collins M (2002). Primary dental care provision in Shetland: current position. Board Paper, Chief Dental Administrative Officer. Shetland NHS Board.

50. Concannon L (2005). Planning for life; involving adults with learning disabilities in service planning. Routledge: London.

51. Cook H (1998). Primary healthcare for people with learning disabilities. *Nursing Times;* 94(30); 54-55.

52. Cooke P (1997). Learning disability. In: *Skidmore D (Ed); Community care: initial training and beyond*. Arnold: London.

53. Cooper M (1997). Mabel Cooper's life story. In: *Forgotten lives – exploring the history of learning disability.* Chapter 2. Atkinson D, Jackson M, Walmsley J (Eds). British Institute of Learning Disabilities publication. Cookley Printers: Worcestershire.

54. Costello P (1988). Dental health status of handicapped children in Galway. *Journal of Dental Research*; 67: 707.

55. Coyle CF, Saunderson W, Freeman RE (2004). Dental students, Social Policy students and learning disability: Do disparate attitudes exist? *European Journal of Dental Education;* 8:133-139.

56. Crow L (1996). Including all of our lives: renewing the social model of disability. In: *Exploring the divide*; Barnes C, Mercer G (Eds). Cambridge University Press: Cambridge.

57. Crowley E, Whelton H, Murphy A, Kelleher V, Cronin M, Flannery E, Nunn J (2003). Oral health of adults with an intellectual disability in residential care in Ireland 2003. Department of Health and Children. Dublin.

58. Crowley E, Whelton H, O'Mullane D, Cronin M, Kelleher V, Flannery E (2005). Parents preference as to whether they would like to accompany their child when receiving dental treatment – results of a national survey. *Journal of the Irish Dental Association*; 51(1): 21-24.

59. Cumella S, Ransford N, Lyons J, Burnham H (2000). Needs of oral care among people with an intellectual disability not in contact with Community Dental Services. *Journal of Intellectual Disability Research*; 44: 45-52.

60. Davies K, Holloway P, Worthington H (1988). Dental treatment for mentally handicapped adults in general practice: parents' and dentists' views. *Community Dental Health,* 5:381-387.

61. Davies N, Duff M (2001). Breast cancer screening in older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research*; 45(3): 253-257.

62. Devlin H, Mellor C, Worthington V (1994). Attitudes of dental students towards elderly people. *Journal of Dentistry,* 22:1 45-48.

63. DHSS (1971). Better services for the mentally handicapped. Cmn 4683. HMSO, London.

64. DHSSPS.NI (2002). Health and social care needs and effectiveness evaluation. Department of Health and Social Services and Public Safety. Belfast.

65. DHSSPS.NI (2005). Equal Lives: draft report of the Learning Disabilities Committee. Department of Health and Social Services and Public Safety. Belfast.

66. DoH (1987) Promoting Better Health. Department of Health. London.

67. DoH (1989). Health services management: future development of Community Dental Services. Health circular HC(89)2. Department of Health. London.

68. DoH (1992). Social care for adults with learning disabilities. HMSO. London.

69. DoH (1994) Improving NHS Dentistry. Department of Health. London.

70. DoH (1995). The Disability Discrimination Act. Department of Health. London.

71. DoH (1997). The NHS Modern. Dependable. Department of Health. London.

72. DoH (1999). Facing the facts: Services for people with learning disabilities, a policy impact study of social care and health services. Department of Health. London.

73. DoH (2000) Promoting Oral Health. Department of Health. London.

74. DoH (2001). Valuing people: a new strategy for learning disability for the 21st century. Cm 5086. Department of Health. London.

75. DoH (2004). National Service Framework for children, young people and maternity services. Disabled children and young people and those with complex health needs. Department of Health. London.
76. DoH (2005).Valuing people: the story so far… a new strategy for learning disability for the 21st century. The Long Report. Department of Health. London.
77. DoH (2007). Valuing people's oral health. Department of Health. London.
78. DoH (2007). Our NHS: our future. Department of Health. London.
79. DoH (2009) Healthy lives, brighter futures – the strategy for children and young people's health. Department of Health. London.
80. Downer MC, Drugan CS, Blinkhorn AS (2006). Salaried services in the delivery of dental care in Western industrialised countries: implications for the National Health Service in England. *International Dental Journal;* 56(1): 7-16.
81. DRC (2006). Disability Rights Commission 2006. Equal treatment: closing the gap. London.
82. Duff M, Hoghton M, Scheepers M (2000). More training is needed in healthcare of people with learning disabilities. *British Medical Journal*, 3, 385.
83. Eberly S (1988). Fairies and the folklore of disability: changelings, hybrids and the solitary fairy. Folklore 99(1):58-77. Cited in Atherton H (2007), A history of learning disabilities. Learning Disabilities: toward inclusion. Gates B (Ed) Elsevier: London.

84. Edwards D, Merry A, Pealing R (2002[1]). Disability Part 2: access to dental services for disabled people. A questionnaire survey of practices in Merseyside. *British Dental Journal*, 193:253-255

85. Edwards D, Merry A, Pealing R (2002[2]). Disability Part 3: improving access to dental practices in Merseyside. *British Dental Journal;* 193(6):317-9.

86. Emerson E, Hatton C, Felce D, Murphy G (2001). Learning disabilities: the fundamental facts. The Foundation for People with Learning Disabilities. London.

87. Erridge P (1986). Dentistry for the handicapped: a survey of current teaching. *British Dental Journal*; 161:261-263.

88. Evans DJ, Greening S, French AD (1991). A study of the dental health of children and young adults attending special schools in South Glamorgan. *International Journal of Paediatric Dentstry*; 1(1): 17-24.

89. FDI (1989). Oral health of the handicapped. Federation Dentaire Internationale. Report of the working group 11: oral health and the handicapped. London.

90. Fenton SJ (1999). People with disabilities need more than lip services. *Special Care In Dentisryt;* 19(5): 198-199.

91. Ferguson FS (1991). Dentists' willingness to provide care for patients with developmental disabilities: a survey of the State graduates of New York at Stony Brook. *Special Care In Dentistry;* 11:234-237.

92. Ferris-Taylor R (2007). Communication: helping people to achieve independence and wellbeing. In: *Learning disabilities: toward inclusion.* Bates, E (2007), Ed. 5th Edition, Elselvier, China.

93. Fido R, Potts M (1997). Using oral histories. In: Forgotten lives – exploring the history of learning disability. Chapter 3. Atkinson D, Jackson M, Walmsley J (Eds). British Institute of Learning Disabilities publication. Cookley Printers. Worcestershire.

94. Forsberg H, Quick-Nilsson I, Gustavson K, Jagell S (1985). Dental health and dental care in severely mentally retarded children. *Swedish Dental Journal*; 9:15-28:

95. Francis JR, Stevenson DR, Palmer JD (1991). Dental health and dental care requirements for young mentally handicapped adults in Wessex. *Community Dental Health;* 8:131-137.

96. Freeman RE (2000). The psychology of dental patient care: the commonsense approach. BDJ Books. London.

97. Freeman RE, Adams E (1991). The prediction of dentists' work behaviour: factors affecting choice or intention in the treatment of special needs patients. *Community Dental Health;* 8: 213-219.

98. Freeman, R., Adams, E., Gelbier, S (1997). The provision of primary dental care for patients with special needs. *Primary Dental Care,* 1:31-34.

99. French S (1994). On equal terms: working with disabled people. Butterworth-Heinemann. Oxford

100. Frewin H (2009).One story. In: *Intellectual disability and social inclusion. A critical review.* Chapter 1. Bollard M (2009) Ed. Elselvier. China.

101. Furnham A, Pendred J (1983). Attitudes towards the mentally and physically disabled. *British Journal of Medical Psychology;* 56: 179-187.

102. Gallagher JE, Fiske J (2007). Special care dentistry: a professional challenge. *British Dental Journal;* 202: 619-629.

103. Garmanikov, E (1978). Sexual division of labour, the case of nursing, in *Feminism and materialism.* Edited by (Kuhn, A., Wolpe, A., 1988). Routeledge: London.

104. Gates, B (2007) (Ed). Learning disabilities: toward inclusion. 5th Edition, Elselvier, China.

105. GDC (2002). *The First Five Years.* London: General Dental Council.

106. Gelb SA (1995). The beast in man: degeneration and mental retardation, 1900-1920. *Mental Retardation;* 33(1): 1-9.

107. Geskie MA, Salasek JL (1988). Attitudes of healthcare personnel toward persons with disabilities. In: *Attitudes toward persons with disabilities*; Yuker H (ed). Springer. New York.

108. Gizani S, Declerck D, Vinckier F, Martens L, Marks L, Goffin G (1997). Oral health condition of 12-year-old handicapped children in Flanders (Belguim). *Community Dental Oral Epidemiology*; 25: 352-357.

109. Goffman E (1961). Asylums: essays on the social situation of mental patients and other inmates. Penguin, Harmondsworth. Cited in Wright D, Digby A (1996). From idiocy to mental deficiency. Routledge. London.

110. Goffman E (1963). Stigma: Notes on the management of a spoiled identity. Cited in Scambler G (1997). Chapter 13; Deviance, sick role and stigma. In: Sociology as applied to medicine; Scambler G (Ed). Saunders, London.

111. Gordon SM, Dionne RA, Snyder J (1998). Dental fear and anxiety as a barrier to accessing oral health care among patients with special health care needs. *Special Care in Dentistry*; 18(2):88-92,.

112. Gordon F, Morgan MZ, Thompson S (2009). A survey of the quality and quantity of Special Care Dentistry teaching, including Gerodontology, in dental schools of the United Kingdom and Ireland. *Journal of Disability and Oral Health;* 10(1): 3-10.

113. Graham F, Kinirons MJ, Holland T (2007). An analysis of the pattern of treatment provided for patients with disabilities requiring treatment under general anaesthesia*. Journal of Disability and Oral Health*; 8: 9-12.

114. Griffiths J (2000). Guidelines for oral care services for people with disabilities: disability and oral care. Nunn, J (Ed). World Dental Press Ltd. London.

115. Griffiths J, Boyle S (1993). Colour guide to holistic oral care, a practical approach*.* London: Mosby Year Book Europe.

116. Gullikson, J (1969). Oral findings of mentally retarded children. *Journal of Dentistry for Children,* 34: 59-64.

117. Hall Carpenter Archives (1989). Inventing Ourselves: Lesbian life stories. London, Routledge.

118. Hally J, Freeman R (2009). A field trial conducted in the Salaried Dental services NHS Highland. Personal communication.

119. Heslop P, Mallet R, Simons K, Ward L (2002). Bridging the divide at transition: what happens for young people with learning disabilities and their families? British Institute for Learning Disabilities. Kidderminster.

120. Higgs R (1972). Attitudes toward persons with physical disabilities as a function of information level and degree of contact. *Disability International*; 16: 1182-1183.

121. HMSO (1979). The Jay Committee report of enquiry into mental handicap nursing and care. Cmnd 7468. London.

122. HMSO (1990). The National Health Service and Community Care Act. London

123. HMSO (1959). The Mental Health Act. London.

124. HMSO (1998). The Human Rights Act. London.

125. HMSO (1989). The Children Act. London.

126. Hogg J (2001). Essential healthcare for people with learning disabilities: barriers and opportunities. *Journal of Rehabilitation and Social Medicine*; 94(7):333-6.

127. Holland TJ, O'Mullane DM (1986). Dental treatment needs in three institutions for the handicapped. *Community Dental Oral Epidemiology*; 14:73-75.

128. Holland T, O'Mullane D (1990). The organisation of dental care for groups of mentally handicapped persons. *Community Dental Health;* 7: 285-293.

129. Holland T, Lucey S, Kavanagh C, O'Mullane D (1996). Costs in providing facilities for treatment of handicapped patients under general anaesthesia. *Journal of the Irish Dental Association*; 43(2): 72-75.

130. Howe Report (1969). Report of the committee of enquiry into allegations of ill treatment of patients and other irregularities at the Ely Hospital, Cardiff, Cmnd 3975. HMSO, London.

131. Hu L, Bentler P (1999). Cut-off criteria for fit indixes in covariance criteria versus new alternatives. *Structural Equation Modelling,* 6: 1-55.

132. Hunter ML, Hunter B, Thompson SA (2004). Attitudes of Specialists in Restorative Dentistry practising in the United Kingdom towards the creation of a new specialty. *Journal of Disability and Oral Health*; 6: 19-24.

133. Johnstone D (2001). An introduction to disability studies. Second edition. Fulton Publishers Ltd. London.

134. Jordan FM, Worrall LE, Hickson LMH, Dodd BJ (2003). The evaluation of intervention programmes for communicatively impaired elderly people. *European Journal of Disorders of Communication*; 28: 63-85.

135. Kane D, Mosca N, Zotti M, Schwalberg R (2008). Factors associated with access to dental care for children with special health care needs. *Journal of the American Dental Association*; 139(3): 326-323.

136. Kaye PL, Fiske J, Bower EJ, Newton JT, Fenlon M (2005). Views and experiences of parents and siblings of adults with Down syndrome regarding oral healthcare: a qualitative and quantitative study. *British Dental Journal*; 198: 571-578.

137. Kendall NP (1991). Oral health of a group of non-institutionalised mentally handicapped adults in the UK. *Community Dental Oral Epidemiology*; 19: 357-359.

138. Kerr A (2005). Building a health service fit for the future: a national framework for service change for NHS Scotland. Edinburgh.

139. Kerr M, Richards D, Glover G (1996). Primary care for people with a learning disability – a group practice survey. *Journal of Applied Research in Intellectual Disability*; 9(4):347-352.

140. Kerrins G, Petrovic K, Gianesini J (2004). Physician attitudes and practices on providing care to individuals with learning disabilities; an exploratory study. *Connecticut Medicine*; 68: 485-490.

141. Keywood K, Flynn M (2006). Healthcare decision making by adults with learning disabilities: ongoing agendas, future challenges. *Psychiatry* 5(10): 360-362.

142. Kinne R, Stiefel, D (1979): Assessment of student attitude and confidence in a program of dental education in care of the disabled. *Journal of Dental Education,* 43: 5, 271-275.

143. Kiyak HA (1988). Impact of patients' and dentists' attitudes on older persons' use of dental services. *Gerodontics;* 4:331-335.

144. Kline R (1998). Principles and practice of structural equation modelling. Guildford Press. New York.

145. Kroll T, Jones GC, Kehn M, Neri MT (2006). Barriers and strategies affecting the utilisation of primary preventive services for people with physical

disabilities: a qualitative inquiry. *Health and Social Care in the Community* 14(4): 284-293.[i]

146. Lee M, Sonis A. (1983). An instrument to assess dental students' attitudes towards the handicapped. *Special Care in Dentistry* 3:117-123.

147. Loan P, Dao BS, Zwetchkenbaum S, Inglehart M (2005). General dentists and special needs patients: does dental education matter? *Journal of Dental Education;* 69(10): 1107-1115.

148. Locker D (1992). The burden of oral disorders in populations of older adults. *Community Dental Health*. 9:109-124.

149. Loeppky WP, Sigal MJ (2006). Patients with special health care needs in general and pediatric dental practices in Ontario. *Journal of the Canadian Dental Association;* 72(10):915.

150. Manthorpe J (1997). Service challenges: the pleasure and problems of alcohol*. Journal of Learning Disabilities for Nursing and Social Care*; 1(1): 31-36.

151. Marks D (1999).The social construction of disability. In; *Disability – controversial debates and psychological perspectives*. Routledge. London

152. Martin GHB, Martin DM (2000). A register for patients with learning disabilities in general practice; workload implications of ex-hospital patients. *Journal of Learning Disabilities*; 4: 37-48.

153. McConkey R, Spollen M, Jamison J (2003). Administrative prevalence of learning disability in Northern Ireland. A report to the Department of Health, Social Services and Public Safety.

154. McIver FT, Machan JB (1979). Prevention of dental disease in handicapped people. In: *Dentistry for the handicapped patient*; Wessels KE(Ed). John Wright PSG Inc. Boston.

155. McNally S (2004). Plus ça change? Progress achieved in services for people with an intellectual disability in England since the publication of Valuing people. *Journal of Learning Disabilities;* 8(4): 323-329.

156. Meehan S, Moore G, Barr O (1995). Specialist services for people with learning disabilities. *Nursing Times*; 91(13): 33-35.

157. Mencap (1998). Health for all? Mencap Health Report, Information Centre. London.

158. Mencap (2004). Treat me right! Better healthcare for people with a learning disability. Mencap. London.

159. Mencap (2007). Death by indifference. Mencap. London.

160. Miller S, Heil J (1976). Effect of an extramural program of dental care for the special patient, on student attitudes. *Journal of Dental Education,* 40:11, 740-744.

161. Milnes AR, Tate R, Perillo E (1995). A survey of dentists and the services they provide to disabled people in the Province of Manitoba. *Journal of the Canadian Dental Association;* 61(2): 149-152.

162. Murray M, Chambers M (1991). Effect of contact on nursing students' attitudes to patients. *Nurse Education Today*; 11(5):363-367.

163. Neugebauer, R (1996). Mental handicap in medieval and early modern England. In: *From idiocy to mental deficiency*. Wright D, Rigby A (1996) (Eds). Routledge. London.

164. Nunn JH (1987). The dental health of mentally and physically handicapped children: a review of the literature. *Community Dental Health;* 4: 157-168.

165. Nunn J (2000). Disability and oral care. International Association for disability and oral health. London.

166. Nunn JH, Murray JJ (1988). Dental care of handicapped children by general dental practitioners. *Journal of Dental Health Education; 52*: 463-465.

167. O'Donnell, D (1993). Use of the SADP for measurement of attitudes of Chinese dental students and dental surgery assistants toward disabled persons. *Special Care in Dentistry,* 13(2): 81-85.

168. Oliver M (1990). The politics of disablement. Macmillan: Basingstoke.

169. Oliver M (1996). Understanding disability: from theory to practice. Macmillan. Basingstoke.

170. Oliver CH, Nunn JH (1996). The accessibility of dental treatment to adults with physical disabilities in Northern England. *Special Care in Dentistry*; 16(5):204-209.

171. Paris MJ (1993). Attitudes of medical students and health professionals towards people with disabilities. *Archives of Physical and Medical Rehabilitation; 7*4: 818-825.

172. Peat M (1997). Attitudes and access: advancing the rights of people with disability. *Canadian Medical Association Journal;* 156:657-659.

173. Pool D (1975). The dental needs of handicapped children. *Royal Society of Health Journal;* 95:175-177.

174. Pool D (1981). Dental care for the handicapped. *British Dental Journal;* 151:267-270.

175. Pool D (1982). Dental care of the handicapped adolescent. *International Dental Journal*; 32: 194-202.

176. Pratelli P, Gelbier S (1998). Dental services for adults with a learning disability: care managers' experiences and opinions*. Community Dental Health;* 15: 281-285.

177. Prime Minister's Strategy Unit (2005). Improving the life chances of disabled people. The Stationary Office. London.

178. Race D (1995). Historical development of service provision. In: *Services for people with learning disabilities;* Malin N (Ed). Routledge. London.

179. Radford JP (1991). Sterilisation versus segregation: control of the feebleminded, 1900-1938*. Social Science and Medicine* 33(4):449-458.

180. RCS England; BSDOH (2001). Clinical Guidelines and Integrated Care Pathways for Individuals with Learning Disabilities. London.

181. Robertson J, Emerson E, Gregory N, Hatton C, Turner S, Kessissoglou S, Hallam A (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities;* 21: 469-486.

182. Romer M, Dougherty N, Amores-Lafleur E (1999). Predoctoral education in special care dentistry: paving the way to better access? *Journal of Dentistry for Children;* 66(2): 132, 135, 138.

183. Roper AG (1913). Ancient Eugenics. Cited by Atherton, H (2007). In: *A history of learning disabilities*. Chapter 3, Learning disabilities: toward inclusion. 5th edition. Gates B (2007) (Ed). Elselvier. China.

184. Scambler G (1997). Sociology as applied to medicine. Ed Scambler G. Saunders, London.

185. Scholle RH (1979). Enabling the disabled. *Journal of the American Dental Association*; 98(3):514.

186. Schuchman L, Overman P (1984). Undergraduate dental hygiene education for special patient care. *Special Care in Dentistry,* Nov/Dec 272-273.

187. Scottish Executive (2000). The Same As You? A review of services for peoplewith learning disabilities. The Stationary Office. Edinburgh.

188. Scottish Executive (2002). Promoting health, supporting inclusion: the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities. The Stationary Office. Edinburgh.

189. Scottish Executive (2003). The Scottish Dental Access Initiative. Edinburgh.

190. Scottish Executive (2006). Review of the primary care Salaried Dental Services in Scotland. Edinburgh.

191. Shakespeare T (2006). Disability rights and wrongs. Routledge. London.

192. Shanley E, Guest C (1995). Stigmatisation of people with learning disabilities in general hospitals. *British Journal of Nursing*; 4(13): 759-760.

193. Shapira J, Efrat J, Berkey D, Mann J (1988). Dental health profile of a population with mental retardation. *Special Care in Dentistry*; 16(4): 149-155.

194. Siegal MD (1985). Dentists' willingness to treat disabled patients*. Special Care In Dentisryt;* 5:102-108.

195. Skipper M (2010). Managed clinical networks. *British Dental Journal*. 209(5): 241-241.

196. Slevin E, Sines D (1996). Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact and graduate-non-graduate status. A comparative study*. Journal of Advanced Nursing*; 24(6): 1116-1126.

197. Sota Rojas AE, Cushings A (1992). Assessment of the need for education and/or training in the dental care of people with handicaps. *Community Dental Health;* 9: 165-170.

198. Speakman HG (1989). A scale for the measurement of attitudes toward physically disabled adults. *International Disability Studies;* 11(3): 133-140.

199. Stanfield M, Scully C, Davison M, Porter S (2003). Oral healthcare to clients with a disability: changes following relocation from hospital to community. *British Dental Journal*: 194: 271-277.

200. Stiefel DJ (1979). Inclusion of a programme of instruction in care of the disabled in a dental school curriculum. *Journal of Dental Education*; 43(5): 262-270.

201. Stiefel DJ, Shaffer SM, Bigelow C (1981). Dentists' availability to treat the disabled patient. *Special Care In Dentistry*; 1:244-249.

202. Stiefel DJ, Rolla RR, Truelove El (1984). Effectiveness of various preventive methodologies for use with disabled persons. *Clinical Preventive Dentistry*; 6: 17-22.

203. Stiff RH, Phipps GT (1964). Attitudes of dental students toward chronically ill and disabled persons. *Journal of Dental Education*; 28(2): 149-154.

204. Storhaug K, Holst D (1987). Caries experience of disabled school-age children. *Community Dental Oral Epidemiology*; 15: 144-149.

205. Smith M, Lennon MA, Brook H, Ritucci L, Robinson PG (2006). Student perspectives on their recent dental outreach placement experiences. *European Journal of Dental Education*; 10: 80-86.

206. Tan RT, Burke FJT (1997). Response rates to questionnaires mailed to dentists. *International Dental Journal*; 47: 349-354.

207. Taylor P (1996). In: *Forgotten lives – exploring the history of learning disability*. Forward. Atkinson D, Jackson M, Walmsley J (Eds). British Institute of Learning Disabilities publication. Cookley Printers. Worcestershire.

208. Taylor M (2006). Review of primary care Salaried Dental services in Scotland. NHS Scotland.

209. Tesini DA, Fenton SJ (1994). Oral health needs of persons with physical or mental disabilities. *Practical Considerations in Special Patient Care*; 38(3): 483-497.

210. Thompson SA, Griffiths J, Hunter ML, Jagger R, Korzun A, McLaughlin A (2001). Development of an undergraduate curriculum in special care dentistry. *Journal of Disability and Oral Health*; 1: 71-77.

211. Thornton C (1996). A focus group inquiry into the perceptions of primary health care teams and the provision of health care for adults with a learning disability living in the community. *Journal of Advanced Nursing*; 23(6): 1168-1176.

212. Tiller S, Wilson KI, Gallagher JE (2001). Oral health status and dental service use of adults with learning disabilities living in residential institutions and in the community. *Community Dental Health*; 18: 167-171.

213. Tizard J, O'Connor N (1952). The occupational adaptation of high-grade detectives. *Lancet* ii:620-623.

214. Tregold A (1909). The feeble-minded – a social danger. Eugenics Review 1:97-104. Cited by Atherton H (2007), A history of learning disabilities. Chapter 3; Learning Disabilities: toward inclusion. Gates B (2007) (Ed). Elsevier: London.

215. UN (1948). Universal Declaration of Human Rights. Geneva.

216. UN (1971). Declaration on the Rights of Mentally Retarded Persons. United Nations General Assembly Resolution.

217. UN (1975). Declaration on the Rights of Disabled Persons. United Nations General Assembly Resolution.

218. Vigid M (1985). Periodontal conditions in mentally retarded children. *Community Dental Oral Epidemiology*; 13:180-182.

219. Vigild M (1986). Dental caries experience among children with Down's syndrome. *Journal of Mental Deficiency Research*; 30: 271-276

220. Waldman HB, Perman SP (2002). Preparing to meet the dental needs of individuals with disabilities. *Journal of Dental Education*; 66: 82-85.

221. Waldman HB, Fenton SJ, Perlman SP, Cinotti DA (2005). Preparing dental graduates to provide care to individuals with special needs. *Journal of Dental Education;* 69(2): 249-254.

222. Waldman HB, Perlman SP (2002). Children with disabilities are aging out of dental care. American Society of Dentistry for Children, *Journal of Dentistry for Children;* 64(6): 385-390.

223. Wasinger J (1986). A personal approach to dental care for patients with handicapping conditions. *Special Care in Dentistry*; Jul-Aug: 156-159.

224. Welsh Assembly (2002). Fulfilling the promises: proposals for a framework for services for people with learning disabilities. Cardiff.

225. WHO (1980). World Health Organisation. International Classification of impairments, disabilities and handicaps; a manual of classification relating to the consequences of disease. Geneva.

226. Wilson K (1992). Treatment accessibility for physically and mentally handicapped people – a review of the literature. *Community Dental Health,* 9: 187-192.

227. Wolfensberger W (1972). The principle of normalisation in human management services. National Institute of Mental Retardation, Toronto.

Cited in Gates, B (2007) (Ed). Learning disabilities: Toward inclusion. 5th Edition, Elselvier, China.

228. Wolff AJ, Waldman HB, Milano M, Perlman SP (2004). Dental students' experiences with and attitudes toward people with mental retardation. *Journal of the American Dental Association*; 135: 353-357.

229. Wright (1980). Developing constructive views of life with a disability. *Rehabilitation Literature*; 41 (11-12): 275-279.

230. Wright D, Digby A (1996). From idiocy to mental deficiency. Routledge. London.

231. Yespen (1941) cited by Race D (1995). Historical development of service provision. In : Malin N(Ed). *Services for people with learning disabilities*. Routledge. London.

232. Yuker H., Block J., Campbell, W (1960). A scale to measure attitudes towards disabled persons (No. 3). Human Resources Foundation. New York.

233. Yuker H (1965) Attitudes as determinents of behaviour. Journal of Rehabilitation; 31:15-16.

10.0 Appendices

10.1 Ethical Approval

-----Original Message-----
From: Queries [mailto:Queries@nationalres.org.uk]
Sent: 29 May 2007 14:54
To: Catherine Coyle
Subject: {Disarmed} RE: Ethical approval?

Thank you.
The following reply has been provided by Jo Downing, Information Officer

Thank you for your query. The Research Governance Framework for Health and Social Care sets out the responsibilities and standards that apply to work managed within the formal research context. Under the Governance Arrangements for NHS Research Ethics Committees (GAfREC), the main role of NHS RECs is to review research involving NHS patients. GAfREC is available on our website at MailScanner has detected a possible fraud attempt from "www.corec.org.uk" claiming to be www.nres.npsa.nhs.uk/applicants/help/guidance.htm <http://www.corec.org.uk/applicants/help/guidance.htm> .

Based on the information provided, we consider the study to be audit and should not be managed as research. Therefore it does not require ethical review by a NHS Research Ethics Committee or approval from the NHS R&D office.

The attached table sets out the criteria we use to distinguish between research, audit and service evaluation.

Although ethical review by a NHS REC is not necessary in this case, all types of study involving human participants should be conducted in accordance with basic ethical principles such as informed consent and respect for the confidentiality of participants. When processing identifiable data there are also legal requirements under the Data Protection Act 2000.

[NHS sites - You should check with the clinical governance office for your organisation what other review arrangements or sources of advice apply to projects of this type. You should ensure that the project is not presented as research in the NHS organisation.]

The above advice does not constitute a form of ethical approval but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you feel that ethical review by a NHS REC is essential, please write setting out

your reasons and we will be pleased to consider further.

I hope this helps.

Regards

Queries Line
National Research Ethics Service (NRES)
National Patient Safety Agency
Website: www.nres.npsa.nhs.uk

Ref: 041/01

10.2 Questionnaire information and consent

Dental Health Sciences Research Unit, University of Dundee.

LEARNING DISABILITIES SURVEY QUESTIONNAIRE

Dear_____,

I am a Specialist Registrar in Paediatric Dentistry in the Belfast Health and Social Care Trust, Northern Ireland. I am presently undertaking a survey of accessibility of primary dental care for adolescents with learning disability in two areas of Northern Ireland and Scotland. This will form part of a Master of Philosophy at the University of Dundee.

I am seeking to gain an understanding of the views and current practices in relation to dental management of adolescents with learning disabilities, of all dentists working within the General Dental Services and Salaried Dental Services. I would be very grateful for your time to complete the enclosed survey, which should take approximately ten minutes. **All answers will be treated confidentially.**

It is hoped that the findings of the survey may help to address the issues of unmet treatment need and waiting lists that presently exist in these separate regions of the UK.

If you are happy to participate, please complete the consent form and return with your completed questionnaire in the enclosed stamped addressed envelope.

Many thanks.

Yours faithfully,

Catherine Coyle

SpR Paediatric Dentistry

Learning disabilities survey questionnaire

Written consent form

Participant number ☐☐☐☐

Please initial all boxes and sign your name to confirm that

The information letter has explained to me what is involved in the study
Please initial box ☐

I have read and understand the information letter
Please initial box ☐

I understand that I can withdraw from the study at any time and for any reason
Please initial box ☐

I agree to take part in the study
Please initial ☐

Name of participant _____

Signature of participant_____ Date _____
(please note that participants must date their own signature)

Dental Health Sciences Research Unit
University of Dundee

LEARNING DISABILITIES AUDIT QUESTIONNAIRE

Learning disability has been described as a significant impairment of intelligence and social functioning acquired before adulthood. People with learning disabilities have an increased prevalence of associated disabilities such as physical or sensory impairments and behavioural problems, which increase their health needs. We would be grateful for your help in answering some questions about adolescents with learning disabilities. Please answer the questions by checking [☑] your response or circling a number [①] as required.

ALL INFORMATION GIVEN IS CONFIDENTIAL

Thank you for your help.

UNIVERSITY OF DUNDEE

NHS Highland

DENTAL HEALTH SERVICES RESEARCH UNIT

Section 1: IN GENERAL

1. What age are you?
   - ☐ 23-27 years
   - ☐ 28-35 years
   - ☐ 36-45 years
   - ☐ 46-55 years
   - ☐ 55+ years

2. Are you?
   - ☐ Male
   - ☐ Female

3. Years since graduation?
   - ☐ <5years
   - ☐ 6-10 years
   - ☐ 11-20 years
   - ☐ 21-30 years

4. University attended?
   - ☐ Glasgow
   - ☐ Dundee
   - ☐ Queen's University Belfast
   - ☐ Other – please state _____

5. Do you have any higher qualifications?
   Please check ☑:as many response as appropriate:
   - ☐ MRCGDP
   - ☐ MFDS
   - ☐ MSc
   - ☐ PhD
   - ☐ M.Phil
   - ☐ Other - please state _____

6. Do you work in?
   - ☐ General dental practice (GDP)
   - ☐ Community/Salaried dental service

7. If you work in GDP, is your practice:
   - ☐ Mainly NHS/NHS Committed
   - ☐ Mainly private practice
   - ☐ Private practice

8. Do you work in?
   - ☐ Northern Ireland
   - ☐ Scotland

9. Are you on a specialist list?
   - ☐ Yes
   - ☐ No

   If yes, which specialty?
   - ☐ Paediatric dentistry
   - ☐ Orthodontics
   - ☐ Oral surgery
   - ☐ Restorative dentistry
   - ☐ Endodontics
   - ☐ Other - please state_____

10. Do you provide Inhalation Sedation?
    - ☐ Yes
    - ☐ No

11a. Do you provide an intravenous (IV) sedation service?
    - ☐ Yes
    - ☐ No

11b. If you <u>do not provide IV</u> do you have access to an IV sedation service?
    - ☐ Yes
    - ☐ No

11c. If you <u>do have access</u> to IV services, how far do your patients have to travel for this service?
    - ☐ 0-5 miles
    - ☐ 6-20 miles
    - ☐ 20-40 miles
    - ☐ >40 miles

12a. Do <u>you have access</u> to a general anaesthetic service?
    - ☐ Yes
    - ☐ No

12b. If you **do have access** to a general anaesthetic service how far do your patients have to travel for this service?

- ☐ 0-5 miles
- ☐ 6-20 miles
- ☐ 20-40 miles
- ☐ >40 miles

13a. Do **you have access** to a specialist dental service for the treatment of adolescent patients with **learning disabilities (LD)**?

- ☐ Yes
- ☐ No

13b. If you **do have access** to a specialist service how far do your adolescent patients with LD have to travel?

- ☐ 0-5 miles
- ☐ 6-20 miles
- ☐ 20-40 miles
- ☐ >40 miles

14. Do you have a specific appointment schedule when treating people with LD?

- ☐ Yes
- ☐ No

15. Is your surgery fully accessible for wheelchair users?

- ☐ Yes
- ☐ No

16. Do you have a hygienist in your practice?

- ☐ Yes
- ☐ No

17. Do you provide information on how to access out of hours emergency dental care for your patients with LD?

- ☐ Yes
- ☐ No

Section 2: DENTAL EDUCATION

1. In your undergraduate training did your course on dental care for the disabled include?

Please check ☑ as appropriate:

- ☐ Hands-on clinical experience with patients with LD
- ☐ Disability awareness training
- ☐ Disability-specific knowledge
- ☐ Communication skills for people with complex communication needs e.g. signing
- ☐ Behavioural management for patients with LDs
- ☐ No formal course on disability

Please answer the following series of questions by checking ☑ *one* answer for each question.

2. Have you attended any postgraduate courses for patients with LD?

- ☐ Yes
- ☐ No

3. Would you welcome postgraduate training in dental care for patients with LD?

- ☐ Yes
- ☐ No

4. It is estimated that in the UK over 1 million people have an LD:

- ☐ True
- ☐ False

5. Approximately 50% of those with LD are profoundly disabled with additional physical disabilities:
   - ☐ True
   - ☐ False

6. More males than females are affected by LD:
   - ☐ True
   - ☐ False

7. In individuals with LD, the poorest periodontal health is found in the 16-19 year age group:
   - ☐ True
   - ☐ False

8 Deinstitutionalisation has increased contact with dental services for those with LD:
   - ☐ True
   - ☐ False

9. General anaesthesia is the treatment of choice for people with LD
   - ☐ True
   - ☐ False

10. Dentists can refuse to accept patients with LDs for treatment on the basis that they may cause upset to other patients:
   - ☐ True
   - ☐ False

11. All dental practices must complete an audit of access to inform of any physical alterations required for compliance with the Disability Discrimination Act (DfES 1995):
   - ☐ True
   - ☐ False

12. Treatment and care for adults with LD unable to give informed consent should be discussed with family, carers or advocates
   - ☐ True
   - ☐ False

Please answer the following series of questions by circling *one* number for each question.

13. How confident are you that you can treat patients with LD?

Not at all confident						Extremely confident
1	2	3	4	5	6	7

14. How much do you want to treat patients with LD?

Not at All						Yes Definitely
1	2	3	4	5	6	7

15. How stressful is it for you to treat people with LD in your dental practice?

Very stressful						Not at all stressful
1	2	3	4	5	6	7

Section 3: SERVICE PROVISION

1. In the last month have you treated any adolescents (13-18yrs) with LD in your surgery?
   - ☐ Yes
   - ☐ No

2. How many adolescents with LD on average do you treat each month in your practice?
   - ☐ none
   - ☐ <5
   - ☐ 6-10
   - ☐ >10

3. **Adolescents with mild learning disability (MLD)**

People with mild learning disability have low support needs and can lead relatively independent lives.

Do you **intend** to treat adolescent patients with MLD in your surgery?
(Please circle number [Ⓞ] as appropriate)

Not at all						Yes Definitely
1	2	3	4	5	6	7

3a If you treat adolescents with MLD which adolescents do you provide dental health care for in your surgery?
Please check ☑ as appropriate
- ☐ MLD only: no other co-existing conditions.
- ☐ MLD with physical impairment.
- ☐ MLD with physical impairment: wheelchair required.
- ☐ MLD with complex communication needs.
- ☐ MLD with mental health problems e.g. ADD.
- ☐ MLD and medically compromised e.g. epilepsy.

3b. What treatment do you provide?
Please check ☑ as appropriate
- ☐ Examination
- ☐ Emergency pain relief only
- ☐ Scale and polish
- ☐ Fillings
- ☐ Extractions
- ☐ Dentures
- ☐ Endodontics
- ☐ Crown and bridgework
- ☐ Other - please state _____
- ☐ No treatment

3c. Where do you refer MLD patients?
Please check ☑ as appropriate
- ☐ Hospital Dental Service
- ☐ Community DS
- ☐ General Dental Service salaried with special interest
- ☐ General Dental Service non-salaried with special interest
- ☐ Don't refer

3d What treatment do you refer for?
Please check ☑ as appropriate
- ☐ Prosthetics
- ☐ Periodontics
- ☐ Conservation
- ☐ Oral Surgery
- ☐ Oral Medicine
- ☐ Orthodontics
- ☐ GA extractions
- ☐ GA conservation

4. **Adolescents with moderate learning disability (MoLD)**

People with moderate learning disability require assistance with some everyday skills, but can undertake a number of tasks themselves independently.

Do you **intend** to treat adolescent patients with MoLD in your surgery?
(Please circle number [⓪] as appropriate)

Not at all						Yes Definitely
1	2	3	4	5	6	7

4a. If you treat adolescents with MoLD which adolescents do you provide dental health care for in your surgery?
Please check ☑ as many as appropriate

- ☐ MoLD only: no other co-existing conditions.
- ☐ MoLD with physical impairment.
- ☐ MoLD with physical impairment: wheelchair required.
- ☐ MoLD with complex communication needs.
- ☐ MoLD with mental health problems e.g. behavioural management problems.
- ☐ MoLD and medically compromised e.g. epilepsy, cardiac disease

4b. What treatment do you provide?
Please check ☑ as appropriate

- ☐ Examination
- ☐ Emergency pain relief only
- ☐ Scale and polish
- ☐ Fillings
- ☐ Extractions
- ☐ Dentures
- ☐ Endodontics
- ☐ Crown and bridgework
- ☐ Other - please state _____
- ☐ No treatment

4c. Where do you refer patients with MoLD who you do not treat?
Please check ☑ as appropriate

- ☐ Hospital Dental Service
- ☐ Community DS
- ☐ General Dental Service salaried with special interest
- ☐ General Dental Service non-salaried with special interest
- ☐ Don't refer

4d. What treatment do you refer for?
Please check ☑ as appropriate

- ☐ Prosthetics
- ☐ Periodontics
- ☐ Conservation
- ☐ Oral Surgery
- ☐ Oral Medicine
- ☐ Orthodontics
- ☐ GA extractions
- ☐ GA conservation

5. **Adolescents with severe learning disability (SLD)**

People with severe LD have high support needs, typically requiring 24-hour care. They may have physical and/or sensory difficulties as well as significant health problems.

Do you **intend** to treat adolescent patients with SLD in your surgery?
(Please circle number [⓪] as appropriate)

Not at all						Yes Definitely
1	2	3	4	5	6	7

5a. What treatment do you provide for adolescents with SLD in your surgery?
Please check ☑ as appropriate

- ☐ Examinations only
- ☐ Emergency pain relief only
- ☐ Scale and polish
- ☐ Fillings
- ☐ Extractions
- ☐ Dentures
- ☐ Endodontics
- ☐ Crown and bridgework
- ☐ Other - please state _____
- ☐ No treatment

5b. Where do you refer patients with SLD?
Please check ☑ as appropriate

- ☐ Hospital Dental Service
- ☐ Community DS
- ☐ General Dental Service salaried with special interest
- ☐ General Dental Service non-salaried with special interest
- ☐ Don't refer

5c. What treatment do you refer for?
Please check ☑ as appropriate

- ☐ Prosthetics
- ☐ Periodontics
- ☐ Conservation
- ☐ Oral Surgery
- ☐ Oral Medicine
- ☐ Orthodontics
- ☐ GA extractions
- ☐ GA conservation

Section 4:
ATTITUDES AND LEARNING

Strongly disagree	Disagree	Neither/nor	Agree	Strongly agree
1	2	3	4	5

Please answer the following questions thinking of your experience of people with LD : Please circle number [Ⓞ] as appropriate:

1	People with a learning disability can be expected to reach the same standard of oral hygiene as other people .	1 2 3 4 5
2	People with a learning disability are able to make decisions about their own health care .	1 2 3 4 5
3	It is impossible to keep the teeth dry when working on people with a learning disability	1 2 3 4 5
4	Patients with a learning disability are too disruptive in the dentist's chair to allow proper treatment	1 2 3 4 5
5	Oral hygiene instruction for people with a learning disability has little or no effect	1 2 3 4 5
6	Aesthetic dental treatment is as important for people with a learning disability as it is for other people	1 2 3 4 5
7	People with a learning disability are able to successfully adjust to life outside an institutional setting	1 2 3 4 5
8	Dentists should reserve the right not to treat people with a learning disability	1 2 3 4 5
9	Patients with a learning disability pose no special health risks to other patients and dental personnel	1 2 3 4 5
10	Dentists should be paid a lot more for treating people with a learning disability than for treating other people	1 2 3 4 5
11	People with a learning disability can be trusted to keep their dental appointments as much as anyone else	1 2 3 4 5
12	Treating people with a learning disability is highly rewarding	1 2 3 4 5
13	Patients with a learning disability upset other patients in the waiting room	1 2 3 4 5
14	Dentists should refuse to treat people with a LD unless they are accompanied by a responsible person	1 2 3 4 5
15	Each dental case should be assessed individually irrespective of whether the patient has a learning disability	1 2 3 4 5
16	Laws should be enforced to prevent dentists from discriminating against people with a learning disability	1 2 3 4 5
17	There is no point in discussing a treatment plan with people with a learning disability, as they will not understand it	1 2 3 4 5
18	Treating patients with a learning disability causes too much stress for the dental team .	1 2 3 4 5
19	It is better for all concerned if people with a learning disability attend specialist clinics rather than general dental practices	1 2 3 4 5
20	People with a learning disability should receive the same quality of care as others	1 2 3 4 5

Please answer the following questions thinking of your experience of people with LD: Please circle number [Ⓞ] as appropriate:

1	Those with learning disabilities should not be entitled to an education	1 2 3 4 5
2	Those with learning disabilities are not more accident prone than other people	1 2 3 4 5
3	An individual with a learning disability is not capable of making moral decisions	1 2 3 4 5
4	Those with learning disabilities should be prevented from having children	1 2 3 4 5
5	Those with learning disabilities should be allowed to live where and how they choose	1 2 3 4 5
6	Adequate housing for individuals with learning disabilities is neither too expensive nor too difficult to build	1 2 3 4 5
7	Living skills programmes for those with learning disabilities are too expensive to operate	1 2 3 4 5
8	People with learning disabilities are in many ways like children	1 2 3 4 5
9	Individuals with learning disabilities need only the proper environment and opportunity to develop and express criminal tendencies	1 2 3 4 5
10	Most people with learning disabilities are willing to work	1 2 3 4 5
11	Adults with learning disabilities should be voluntarily committed to an institution following arrest	1 2 3 4 5
12	Individuals with learning disabilities are able to adjust to life outside an institutional setting	1 2 3 4 5
13	Those with learning disabilities should live with others of a similar disability	1 2 3 4 5
14	Group homes for those with learning disabilities should not be prohibited in residential districts	1 2 3 4 5
15	The opportunity for employment should be provided to individuals with learning disabilities	1 2 3 4 5
16	Children with learning disabilities in mainstream education have an adverse effect on other children	1 2 3 4 5
17	Simple repetitive work is appropriate for those with learning disabilities	1 2 3 4 5
18	People with learning disabilities show a deviant personality profile	1 2 3 4 5
19	Individuals with learning disabilities engage in bizarre and deviant sexual activity	1 2 3 4 5
20	Workers with learning disabilities should receive at least the minimum wage established for their jobs	1 2 3 4 5
21	Individuals with learning disabilities can be expected to fit into competitive society	1 2 3 4 5
22	Very little sensitivity is required when interacting with those with learning disabilities	1 2 3 4 5
23	Individuals with learning disabilities make other people feel uneasy	1 2 3 4 5
24	When working with people with learning disabilities, it is hard to respond to them	1 2 3 4 5

Please make sure that you have answered all the questions

Thank you for your help

10.3 Univariant Analysis of Variance: Influence of area, age and gender

Table 1: Comparison of undergraduate training experience in special care dentistry by gender, age groups and area of work

Tests of Between-Subjects Effects

Dependent Variable: trainingUG

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	20.971(a)	11	1.906	2.788	.002
Intercept	147.322	1	147.322	215.420	.000
recodegender	.012	1	.012	.018	.893
Recodecountry	.454	1	.454	.663	.416
Recodeagegroup	14.934	2	7.467	10.918	.000
recodegender * Recodecountry	.022	1	.022	.033	.856
recodegender * Recodeagegroup	1.592	2	.796	1.164	.314
Recodecountry * Recodeagegroup	.756	2	.378	.553	.576
recodegender * Recodecountry * Recodeagegroup	.379	2	.190	.277	.758
Error	196.959	288	.684		
Total	781.000	300			
Corrected Total	217.930	299			

a R Squared = .096 (Adjusted R Squared = .062)

Table 2:Comparison of total knowledge score: provision of special care dentistry by gender, age group and area of work

Tests of Between-Subjects Effects

Dependent Variable: total knowledge

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	42.574(a)	11	3.870	1.486	.136
Intercept	3053.836	1	3053.836	1172.528	.000
agecatergory_3	1.601	2	.800	.307	.736
country	.104	1	.104	.040	.842
sex	2.959	1	2.959	1.136	.287
agecatergory_3 * country	.686	2	.343	.132	.877
agecatergory_3 * sex	2.519	2	1.259	.484	.617
country * sex	19.740	1	19.740	7.579	.006
agecatergory_3 * country * sex	14.558	2	7.279	2.795	.063
Error	750.093	288	2.604		
Total	12826.000	300			
Corrected Total	792.667	299			

a R Squared = .054 (Adjusted R Squared = .018)

Table 3:Comparison of willingness to treat adolescents with LD: provision of special care dentistry by gender, agegroup and area of work

Tests of Between-Subjects Effects

Dependent Variable: willlingnessscale

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1875.965[a]	11	170.542	3.096	.001
Intercept	44658.084	1	44658.084	810.725	.000
sex	412.781	1	412.781	7.494	.007
country	3.620	1	3.620	.066	.798
agecatergory_3	366.458	2	183.229	3.326	.037
sex * country	72.362	1	72.362	1.314	.253
sex * agecatergory_3	122.255	2	61.127	1.110	.331
country * agecatergory_3	464.877	2	232.438	4.220	.016
sex * country * agecatergory_3	335.340	2	167.670	3.044	.049
Error	14597.291	265	55.084		
Total	170553.000	277			
Corrected Total	16473.256	276			

a. R Squared = .114 (Adjusted R Squared = .077)

Table 4: Influence of area of work, gender and age group on total mean clinical factor scores.

Tests of Between-Subjects Effects

Dependent Variable: clinical treatment factor

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	915.318[a]	11	83.211	2.759	.002
Intercept	49507.701	1	49507.701	1641.740	.000
recodegender	193.191	1	193.191	6.406	.012
Recodecountry	60.804	1	60.804	2.016	.157
Recodeagegroup	100.379	2	50.190	1.664	.191
recodegender * Recodecountry	18.904	1	18.904	.627	.429
recodegender * Recodeagegroup	6.861	2	3.430	.114	.893
Recodecountry * Recodeagegroup	5.656	2	2.828	.094	.911
recodegender * Recodecountry * Recodeagegroup	60.783	2	30.391	1.008	.366
Error	8684.822	288	30.156		
Total	202957.688	300			
Corrected Total	9600.141	299			

a. R Squared = .095 (Adjusted R Squared = .061)

Table 5: Influence of area of work, gender and age group on total mean social factor scores.

Tests of Between-Subjects Effects

Dependent Variable: social treatment factor

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	406.101[a]	11	36.918	1.513	.126
Intercept	107398.143	1	107398.143	4401.525	.000
recodegender	49.294	1	49.294	2.020	.156
Recodecountry	44.584	1	44.584	1.827	.178
Recodeagegroup	81.075	2	40.537	1.661	.192
recodegender * Recodecountry	.636	1	.636	.026	.872
recodegender * Recodeagegroup	4.064	2	2.032	.083	.920
Recodecountry * Recodeagegroup	27.781	2	13.890	.569	.567
recodegender * Recodecountry * Recodeagegroup	13.363	2	6.682	.274	.761
Error	7027.262	288	24.400		
Total	420337.813	300			
Corrected Total	7433.362	299			

a. R Squared = .055 (Adjusted R Squared = .019)

10.4 Attitudinal dimension: Coyle (2004) scale

This scale has been used previously to determine the attitudes of a sample of undergraduate dental students and social policy students, showing good reliability and ease of administration (Coyle at al, 2004). It is composed of 24 items, concerning general attitudes towards individuals with learning disabilities in the community setting.

All the scores for the 24 attitudinal items were subjected to a principle components analysis. Two components were identified which explained 28.42% of the total variance. Scale 1 was composed of items 2, 5, 6, 10, 12, 14, 15, 20, 21, collectively making an 'enabling' scale. It explained 22.12% of the variance and had an eigenvalue of 5.31. Scale 2 was composed of items 1, 3, 4, 7,8, 9, 11, 13, 16, 17, 18, 19, 22, 23, 24, and reflected the 'disabling' perspective of participants' attitudes. It explained 6.31 % of the variance, with an eigenvalue of 1.51. Internal consistency and reliability of the two scales however, was found to be inadequate, with the 'enabling' scale having a Cronbach α value of 0.50, and the 'disabling' scale having a Cronbach α value of 0.60 Given the poorer internal consistency of the scales ,further analyses were not conducted. A summary of means, 95% confidence intervals, reliabilities, and loadings for each of the individual scale items, is included in Table 6.

Table 6: Twenty-four item attitude questionnaire: Coyle scales (reliabilities), and items (means, standard deviations and factor loadings)

	Cronbach alpha	Factor loading	Mean (SD)
Scale 1: Enabling attitudes	**0.50**		**32.05 (3.79)**
Those with LD are not more accident prone than other people		0.04	2.93 (0.87)
Those with LD should be allowed to live where and how they please		0.61	3.41 (0.95)
Adequate housing for individuals with LD is neither too expensive nor too difficult to build		0.33	3.33 (0.89)
Most people with LD are willing to work		0.56	3.68 (0.66)
Individuals with LD are able to adjust to life outside an institutional setting		0.63	3.69 (0.72)
Group homes for those with LD should not be prohibited in residential areas		0.02	3.48 (1.07)
The opportunity for employment should be provided to individuals with LD		0.47	4.19 (0.65)
Workers with LD should receive at least the minimum wage established for their jobs		0.42	4.27 (0.78)
Individuals with LD can be expected to fit in to competitive society		0.59	3.08 (0.80)
Scale 2: Disabling attitudes	**0.60**		**32.59 (7.20)**
Those with LD should not be entitled to an education		0.21	1.32 (0.86)
An individual with a LD is not capable of making moral decisions		0.40	1.99 (0.79)
Those with LD should be prevented from having children		0.30	1.99 (0.92)
Living skills programmes for those with LD are too expensive to operate		0.50	2.34 (0.77)
People with LD are in many ways like children		0.61	2.92 (0.90)
Individuals with LD need only the proper environment and opportunity to develop and express criminal tendencies		0.51	2.01 (0.90)
Adults with LD should voluntarily be committed to an institution following arrest		0.34	1.98 (0.89)
Those with LD should live with others of a similar disability		0.22	2.43 (0.80)
Children with LD in mainstream education have an adverse effect on other children		0.37	2.53 (2.05)
Simple repetitive work is appropriate for those with LD		0.80	2.69 (0.80)
People with LD show a deviant personality profile		0.80	1.89 (0.83)
Individuals with LD engage in bizarre and deviant sexual activity		0.49	1.79 (0.80)
Very little sensitivity is required when interacting with those with LD		0.29	1.90 (0.82)
Individuals with LD make other people feel uneasy		0.58	2.77 (0.96)
When working with people with LD, it is hard to respond to them		0.19	2.14 (0.81)